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ABSTRACT

This report is the product of a project that examined services to people with disabilities living on American Indian or Alaska Native (AI/AN) tribal lands. Research such as the American Indian Disability Legislative Project and other studies on health, rehabilitation, independent living, and education issues that affect people with disabilities living in Indian country were surveyed. It also considered views and perspectives of AI/AN people with disabilities, tribal leaders, and federal agency representatives. This report reviews the literature, reports on interviews with stakeholders, and examines and recommends improvements in government-to-government (including sovereign tribal governments) relationships. The report makes the following major recommendations: (1) fulfill the federal trust responsibility to AI/AN tribes and the national mandate for the elimination of discrimination against individuals with disabilities; (2) ensure meaningful consultation and involvement of people with disabilities and tribal leaders; (3) provide tribes with better access to federal resources and funded programs; (4) develop cultural competence within federal agencies and increase agencies' interaction with tribes; (5) include disability issues among tribal priorities and federal initiatives in tribal communities. Seven appendices provide additional documentation such as interview guides, case studies, and community stories of innovation. (DB)

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People with Disabilities on Tribal Lands:

Education, Health Care, Vocational Rehabilitation, and Independent Living

National Council on Disability

August 1, 2003

EC 309863

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People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living

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NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

LETTER OF TRANSMITTAL

August 1, 2003

The President
The White House
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit to you this special report entitled *People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living*. We are particularly proud of this report because it reflects the results of a project that was developed and guided to completion in conference with American Indian and Alaska Native (AI/AN) representatives of people with disabilities, their families, and tribal community leaders.

NCD has targeted the significant, unmet needs of unserved and underserved people with disabilities, including people from diverse cultures, as a policy priority. While people from diverse cultures constitute a disproportionate share of the disability community, they also have unique needs in addition to those experienced by other people with disabilities. At 22 percent prevalence, according to national research data, American Indians and Alaska Natives have the most disproportionate rate of disabilities of all population groups, compounded by factors such as high poverty and school dropout rates, geographic isolation from state or local district rehabilitation and health care, and limited employment options.

This project examined research on health, rehabilitation, independent living, and education issues that affect people with disabilities living in Indian Country. The report discusses views and perspectives of AI/AN people with disabilities, tribal leaders, and federal agency representatives identified as productive in meeting the needs of people with disabilities residing in tribal lands. This report also assesses and recommends government-to-government (state to sovereign tribal to U.S. government) improvements in relationships needed for effective coordination across existing federally funded projects/programs. In addition, a Toolkit guide providing resource information was developed for use by consumers, tribal communities, and people at state, local, and federal levels.

NCD stands ready to facilitate federal agency dialogue with stakeholders who seek to address jointly the unmet needs of American Indians and Alaska Natives with disabilities in meaningful and culturally sensitive ways. It is only then that we can rest assured that all of our citizens with disabilities have the freedom to fulfill their dreams, access economic independence, and participate meaningfully in their communities.

Sincerely,

Lex Frieden

Lex Frieden
Chairperson

(This same letter of transmittal was sent to the President Pro Tempore of the Senate and the Speaker of the House of Representatives.)

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Acknowledgments

The National Council on Disability's (NCD) project, *People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living,* was formed and guided by the powerful sharing of experiences, knowledge, and hopes of American Indian people with disabilities, their families, and advocates. These individuals strived to create a new perspective about what it means to be an American Indian and Alaska Native with a disability. This new consciousness will serve to transform Indian communities nationally and offer a new hope to so many individuals who for so long have felt invisible and not heard.

NCD expresses its gratitude to the team at Kauffman and Associates, Inc., for drafting this report. Team members include Ann Kauffman, president; Project Director Martina Whelshula; Victor Paternoster; Tim Spellman; Wendy Thompson; and Ara Walline.

Others who supported the development of this work and deserve special acknowledgment are Mike Blatchford, consultant; Desautel Hege Communications; Kathy Langwell and Project HOPE; Robert Shuckahosee, consultant; Frank Ryan, consultant; the Consortia of Administrators for Native American Rehabilitation (CANAR); the American Indian Disability Technical Assistance Center; the American Indian Rehabilitation Research Training Center; the National Congress of American Indians (NCAI); focus group participants at NCAI and CANAR conferences; and Judy Babbit from the City of San Antonio Disability Access Office.

A special acknowledgment goes to those who represent the heart and soul of this effort, our Technical Expert Panel members Mark Azure, Julie Clay, Julia Davis-Wheeler, LaDonna Fowler, Joanne Francis, Joseph Garcia, Cordia LaFontaine, Carol Locust, Danny Lucero, David Miles, Damara Paris, Andrea Siow, H. Sally Smith, Raho Williams, and Alvin Windy Boy. Thank you to Jessie Stewart, age 10, for sharing her story.

In attempts to understand the complex make-up of Indian Country as it addresses the needs of tribal members and descendants with disabilities, tribal program directors shared willingly about the challenges and inspirations experienced in their work. NCD acknowledges these people and the tribes they represent: Jo White, Oglala Nation at Pine Ridge; Arlene Templer, Confederated

Salish and Kootenai Tribes; Rita LaFrance, St. Regis Mohawk; Rhonda Talaswaima, Hopi Nation; Ela Yazzie-King and Paula Seanez, Navajo Nation; Darlene Finley, Three Affiliated Tribes; Linda Pratt, Yakama Nation; Larry Alflen, Pueblo of the Zuni; Steven "Corky" West, Oneida Nation; and Len Whitebear, Cook Inlet Tribal Council.

Federal and regional officials contributed to an increased awareness of practices that promote government-to-government relationships. NCD acknowledges those agencies that offered their insights into the delicate circumstances of improving government-to-government relationships between tribes and federal/state governments. Those agencies who contributed were Indian Health Service, Elder Care; Region X, Rehabilitation Services; BIA, Special Education; Indian Health Service, Public Health; American Indian and Alaska Native Social Security; Administration for Native Americans; and Administration on Aging, Native American Programs.

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SECTION I

Preface

Among the strategies and decisions that emerged from the National Council on Disability's May 2000 think-tank process was a commitment by people with disabilities from diverse cultures, supporters from national advocacy groups, and the U.S. Congress to (1) investigate different approaches to advancing disability, civil, and human rights and (2) develop an informational toolkit with attention to different cultural needs.

American Indian and Alaska Native (AI/AN) people with disabilities, particularly those who live in Indian country, face unique circumstances and legal environments that require special outreach and consultation in addition to the development of culturally appropriate methods and tools to address their unmet needs for services and support. This project, *People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living,* was intended to facilitate consultation and input from AI/AN people with disabilities, tribal leaders, and community organizations, to obtain information, and to recommend strategies for improving services to people with disabilities who live in Indian Country. In addition, the project developed a culturally appropriate Toolkit, specifically designed to address the unique political and legal foundations of AI/AN tribal communities. The Toolkit provides background on education, health, vocational rehabilitation, independent living, and other services important to people with disabilities; model approaches; and supporting documentation for improving services and support to people with disabilities living in Indian Country.

> *"As a child when I moved to a deaf school off tribal lands I couldn't participate in my cultural rituals such as powwows and ceremonies. My life was like a torn piece of paper. When I could reconnect these ceremonies and my ability to be first a Native American and then a deaf person—my life came together again."*
>
> *—Mark Azure, Intertribal Deaf Council*

SECTION II

Executive Summary

"My disabilities are perceived by my American Indian and Alaska Native peers as a part of me. I do not feel as stigmatized as I do in mainstream society. At the same time, powwows and community tribal events are not sign language interpreted. How can I learn my traditions from my people without communication support?"

—Damara Paris, Intertribal Deaf Council

In passing the 1990 Americans with Disabilities Act (ADA), Congress announced its purpose to provide "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." This national mandate for the elimination of discrimination ignored the unique circumstances faced by American Indians and Alaska Natives with disabilities living in tribal lands. Caught in a public policy paradox, American Indian and Alaska Native (AI/AN) people with disabilities are stuck between the sometimes conflicting priorities of protecting the sovereignty of tribal governments and ensuring the civil rights guaranteed to all people with disabilities.

AI/AN tribes are sovereign governments and enjoy a unique government-to-government relationship with the United States that is based upon treaties, the U.S. Constitution, federal law, executive orders, and affirming court decisions. In addition to this unique legal status, Indian Country is disproportionately rural, which poses a number of logistical and resource challenges to the provision of and access to social, health, and support services. Historically, American Indians and Alaska Natives tend to have less education, greater unemployment, and higher rates of poverty than people of other racial groups in the United States. Meeting the needs of people with disabilities living in Indian Country requires recognition of the unique legal and socioeconomic environment of tribal communities, as well as an understanding of various AI/AN cultures and history that shape each community. Appropriate consultation and input from tribal leaders and tribal members with disabilities is critical in understanding the depth and complexity of AI/AN cultures. The activities undertaken through this project explored the complex weave of

federal disability laws, tribal sovereignty, tribal cultures, perspectives of AI/AN people with disabilities, and the diverse economic and physical environments in which they find themselves.

The American Indian Disability Legislative Project (AIDLP) reports that only 6 percent of tribal governments surveyed are familiar with major disability legislation, such as ADA or Sections 503 and 504 of the Rehabilitation Act of 1975. The survey responses indicate that only two-thirds of the tribal schools, stores, churches, and other buildings were accessible to people with disabilities. Lack of employment opportunities, transportation, financial resources, and elevated health care costs all add to the numerous inequities faced by people with disabilities living in Indian Country.

This National Council on Disability (NCD) project examined research such as the AIDLP and other studies and reports on health, rehabilitation, independent living, and education issues that impact people with disabilities living in Indian Country. In addition, this report discusses views and perspectives of AI/AN people with disabilities, tribal leaders, and federal agency representatives identified as productive in meeting the needs of people with disabilities residing in tribal lands. Finally, this report assesses and recommends government-to-government (state to sovereign tribal to U.S. government) improvements in relationships needed for effective coordination across existing federally funded projects/programs.

Summary of Research Findings

> *"Everybody has his or her own unique gifts. It is up to us to find our path. We must show others and teach people to look beyond differences and find good in everyone."*
>
> *—Andrea Siow, Hopi Nation*

According to the 2000 U.S. Census, nearly 2.5 million Americans identify themselves exclusively as "American Indian or Alaska Native." There are 4.1 million people who identify themselves either as Indian only or as Indian in combination with another race. Of this total, approximately 944,433 Indian or Alaska Native people live on federal reservations or on off-reservation trust lands. Thirty-five states have federal reservations within or overlapping state borders. The Federal Government, through the Bureau of Indian Affairs (BIA), officially

recognizes 560 tribes and Alaska Native villages. They are known as "Federally Recognized Tribes."

Data from the 1997 Survey of Income and Program Participation found that 22 percent of the AI/AN population have one or more disabilities. If we consider the 2.5 million who reported on the 2000 census that they identify themselves exclusively as "American Indian or Alaska Native," this means that at least 550,000 American Indians and Alaska Natives have disabilities.

Every type of disability that is found in the general population can also be found in the AI/AN population. Several small studies have surveyed tribal communities to identify the most frequent types of disabilities. These studies generally found that the following types of disabilities are most often reported in Indian community surveys: spinal cord injury; diabetes complications; blindness; mobility disability; traumatic brain injury; deafness or hardness of hearing; orthopedic conditions; arthralgia; emotional or mental health concerns; learning disabilities; and alcoholism or drug dependence.

This NCD project sought to bring our understanding of people with disabilities living in tribal lands closer to the community level. The project tapped the knowledge and experience of a Technical Expert Panel (TEP) to begin to identify the major issues related to health, education, vocational rehabilitation, and independent living for people with disabilities in Indian Country. In consultation with the TEP, 10 Indian communities were identified for individual tribal interviews as follows: Confederated Salish and Kootenai Tribes of the Flathead Reservation (MT), Cook Inlet Tribe (AK), Hopi Nation (AZ), Navajo Nation (AZ, NM, UT), Oglala Sioux Tribe (SD), Oneida Nation (WI), The Pueblo of Zuni (NM), St. Regis Mohawk (NY), Three Affiliated Tribes at Fort Berthold (ND), and Yakama Nation (WA).

These tribal interviews uncovered specific strategies and programs implemented at the local community level that have effectively improved access, protections, and services for people with disabilities in tribal communities. Several tribes, such as the Salish and Kootenai Tribes in Montana, the Oglala Sioux Tribe in South Dakota, and the Navajo Nation in the Southwest, have adopted tribe-specific ordinances to establish protections and services for people with disabilities in their communities. The Hopi Nation in Arizona and the St. Regis Mohawk in New York

provide active case management approaches with extensive outreach and grassroots consumer involvement. The Pueblo of Zuni of New Mexico place a high priority on public transportation services as the key to providing assistance and advocacy for people with disabilities. Six key elements emerged as common practices across promising programs. These are summarized below.

Key Elements of Promising Practices in Indian Country

"The consumers are the leadership. Learn from the consumer."

—Steven 'Corky' West, Oneida Nation

- *Effective program leadership characteristics:* At the tribal community level, leaders of promising programs commonly embody qualities of passion, perseverance, vision, commitment, change agents, consistency, connection to consumers, and a sense of hope.

- *Responsiveness to the consumer:* Members of program staffs embrace people with disabilities as a part of their teams, developing relationships and shared power in the planning and implementation of services and programs.

- *Innovation in removing barriers:* Breaking down barriers and reshaping tribal communities require personal and collective creativity/inventiveness and risk taking. The reshaping of resources can help to provide a seamless array of supports, programs, and services for people with disabilities.

- *Effective collaboration:* Program staff communication and coordination with other nontribal resources recognize the role of services and resources outside the realm of individual programs or communities and seek to build bridges among separate entities. This also requires personal relationship building.

- *Advocacy strength:* It is important to instill a strong sense of advocacy into the program philosophy and staff approaches to policy and program implementation. The

multiple and disjointed systems that impact people with disabilities require strong self-advocates and supporters to navigate administrative barriers.

- *Support from tribal leadership:* A common ingredient is strong and committed leadership from elected tribal officials, although each tribe interviewed for this report operated differently in its approach to meeting the needs of tribal members with disabilities.

Barriers and Challenges to Effective Government-to-Government Relationships

> *"Sometimes when an elder leaves the home to live in an institutional setting their spirit is just lost. The foundation of the family is gone and the cultural unity of the family suffers. When it is appropriate, day care can help elders and we can see a difference with this personal care. We have a lot of work to do to be recognized and know how to access services like these."*
>
> *—Raho Williams, Navajo*

Federal laws designed to protect people with disabilities are not always enforceable against tribal governments because of the sovereign immunity and sovereign status that tribal governments enjoy. The U.S. Supreme Court has yet to rule on whether or not and to what extent federal disability laws apply to Indian tribes. In the absence of that, different and sometimes conflicting opinions are being developed in lower courts. In addition, the services and resources that should be available to people with disabilities are not always accessible in tribal communities. Chronic underfunding of tribal community programs and a lack of physical infrastructure upgrades create barriers for people with disabilities in these communities. This NCD report identified barriers and challenges that hamper or prevent meaningful government-to-government relationships to develop among tribes and state or federal entities. Such relationships can help governments better address jointly some of the issues related to people with disabilities in Indian Country. Based upon a review of the literature, interviews with tribal officials, and interviews with federal program administrators, the following major barriers were identified:

Disjointed coordination among agencies:

- Fragmentation of services across federal agencies and offices
- Lack of coordination and collaboration among federal, state, and tribal programs
- Federal travel and budget limitations
- Advocacy made difficult by multiple education systems (public, BIA, tribal)

Limited knowledge or understanding about tribal communities:

- Lack of federal staff knowledge and training for federal personnel on the federal trust responsibility to AI/AN people and on tribal sovereignty
- Agency staff fear of the unknown and unfamiliarity with AI/AN populations

Limited enforcement of laws protecting people with disabilities on tribal lands:

- Lack of clarity about legal enforcement options
- Failure to ensure that the national mandate to eliminate discrimination against individuals with disabilities included equal benefits for American Indian and Alaska Natives with disabilities

Limited local tribal planning to protect and support people with disabilities:

- Lack of involvement of tribal leaders and tribal members in the design, development, and implementation of programs
- Limited consumer involvement at all levels of policy development
- Difficulties in tribal/state relationships
- Limited tribal awareness and access to new strategies that can better serve people with disabilities
- Historical distrust of the Federal Government by tribal leaders and members

Key Findings and Recommendations

"You have control. Just ask for what you need."

—Jo White, Quad Squad, Oglala Sioux Tribe

It is important to note that this NCD study found a very active and articulate network of AI/AN people with disabilities who are working through a variety of local and national organizations to bring important resources to their communities and to reshape the way tribal governments address their issues. Examples are numerous, including a one-person sit-in on the steps of a tribal building to force the tribe to construct a ramp sponsored by the Pine Ridge Quad Squad; the development of national research expertise found at the American Indian Rehabilitation Research and Training Center; and the organization of national advocacy groups such as the Intertribal Deaf Council and the American Indian Rehabilitation Rights Organization of Warriors. Through individual self-determination and collective bravery and persistence, changes are occurring in tribal communities. Based in large part on the groundwork performed by the AI/AN disabilities community, this study identified 15 major areas of findings and corresponding specific recommendations to improve government-to-government relationships for the benefit of people with disabilities in tribal communities. Detailed descriptions of these findings and recommendations are provided in subsequent chapters of this report. The following is a summary of the five major categories of recommendations proposed in this report:

Fulfill the federal trust responsibility to AI/AN tribes and the national mandate for the elimination of discrimination against individuals with disabilities:

- *Clarifying application of federal disability laws:* The Department of Justice should provide robust leadership to ensure that the protections of ADA are extended to individuals with disabilities in AI/AN communities, working in close consultation with tribes and AI/AN people with disabilities.

- *Holding federal agencies accountable for information dissemination and service:* Federal agencies must fulfill the federal trust responsibilities to tribes by assertive

efforts to disseminate pertinent information and by developing culturally specific strategies to reach out to tribal communities.

- *Improving coordination and collaboration among programs:* Culturally responsive strategies should be developed among the various federal programs intended to serve people with disabilities to ensure that tribal communities are able to access important services.

Ensure meaningful consultation and involvement of people with disabilities and tribal leaders:

- *Recognizing and valuing tribal and consumer consultation:* Pursuant to the president's Executive Order on tribal consultation, federal agencies should engage tribes and consumers in meaningful consultation to better address issues related to people with disabilities in tribal communities.

- *Improving state and tribal relationships to better serve people with disabilities:* The Department of Education and other federal agencies supporting state programs and initiatives should provide leadership and encouragement to improve state and tribal relationships regarding services to people with disabilities.

- *Convening national meeting(s) of key stakeholders to better address the needs of people with disabilities in tribal lands.* The federal Departments of Justice, Education, Health and Human Services, Transportation, Housing and Urban Development, and Interior should collaborate with tribal leadership and Indian community consumer groups to convene a national summit to begin to address issues raised in this report and to develop ongoing collaboration.

Provide tribes with better access to federal resources and funded programs:

- *Providing tribal communities access to Independent Living Centers:* The Department of Education should provide a specific set-aside in funds to support independent living centers in tribal communities.

- *Increasing access to American Indian Vocational Rehabilitation Services (AIVRS):* Funding for AIVRS must be substantially increased to allow for more tribes to participate in this important program and an increase in technical assistance and support to existing programs.

- *Expanding home- and community-based services options in tribal communities:* The Indian Health Service and Centers for Medicare and Medicaid Services should collaborate to provide necessary training and technical assistance to tribal health care systems to provide home- and community-based services and to decrease unnecessary dependence on institutional care.

Develop cultural competence within federal agencies and increase agencies' interaction with tribes:

- *Expanding cultural competence, training, and orientation:* Each of the federal agencies providing services and programs targeting people with disabilities should ensure staff are trained and oriented to understand and engage tribal communities.

- *Recruitment and hiring of AI/AN professionals and advocates within the federal system:* Specific staff positions to provide liaison between federal programs and tribal communities should be established for federal agencies and programs. In particular, the Social Security Administration should provide a Native American liaison position in each of its federal regional offices for tribal outreach and advocacy.

Include disability issues among tribal priorities and federal initiatives in tribal communities:

- *Increasing employment opportunities for people with disabilities in tribal communities:* Tribal governments should consider ways to create expanded employment opportunities for people with disabilities in their communities.

- *Making all public buildings and public infrastructure in tribal communities accessible to people with disabilities:* Federal departments such as Interior,

Transportation, Housing, and Health and Human Services should collaborate with tribal governments to identify funds to retrofit tribal buildings and infrastructure to ensure tribal communities are accessible to people with disabilities.

Conclusion

Effective collaboration among sovereign tribal governments and federal and state programs is key to successfully addressing the issues and needs of tribal members with disabilities and descendants living in Indian Country. AI/AN people with disabilities and advocates must be invited to the table for key conversations regarding application of disability policies, initiatives, and program development and resource allocation. Unless and until this government-to-government collaboration occurs, AI/AN people with disabilities will continue to remain locked out of the protections and services guaranteed to all Americans with disabilities.

Andrea Siow (Hopi Nation), a TEP member, stated, "By getting the word out that people with disabilities are not helpless, we can create awareness and improve things....It is up to us to find our path...." Self-determination is a fundamental and important principle not only for tribal governments, but for individual tribal members with the human need for opportunity, inclusion, support, access, and freedom to chart one's own course. This nation's mandate to eliminate discrimination against individuals with disabilities has thus far failed to appropriately address the inclusion of AI/AN communities. For many people with disabilities in tribal communities, the freedom to fulfill their dreams, access economic independence, and meaningfully participate in their tribal community may rest in the willingness of tribal, state, and federal governments to work together. Stakeholders will need to work cooperatively and effectively in ways that respect both the mandates and benefits of ADA and other disability laws, as well as this nation's time-honored moral and legal obligations to tribal governments.

SECTION III

Research Findings

Overview

The National Council on Disability (NCD) has made a major and continuing commitment to identifying barriers to access, appropriate services, and supports that differentially affect people with disabilities from diverse cultures. This project reflects that commitment and was intended to provide information and products for consumers and to meet the goals set forth for the project. The project goals included addressing key disability policy issues from a multiprogram, cross-agency perspective; offering culturally competent information to tribal communities based on representative input from tribal people with disabilities and tribal leaders; and suggesting practical models to support the empowerment of people with disabilities.

Despite representing a small percentage of the total U.S. population, American Indians and Alaska Natives enjoy a unique legal, historical, and political relationship with the Federal Government. As indigenous peoples, Indian tribes engaged in government-to-government relationships with other sovereign countries before the United States was established.[1] At its formation, the United States recognized the unique relationship with Indian tribes, and this recognition continues today. Meeting the needs of people with disabilities living in Indian Country requires recognition of these unique relationships and cultures and appropriate consultation with and input from tribal leaders and communities to develop effective and useful service approaches. The activities undertaken throughout this project sought to obtain that necessary consultation and input through culturally responsive and appropriate strategies. The result is information presented in both a report and a Toolkit that form a foundation for long-term development of policies and initiatives that can be used to improve access to services and support for this population.

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[1] See, e.g., *Montoya v. United States*, 180 U.S. 261 (1901).

The stated objectives of this project were to

1. Summarize recommendations from relevant research and reports on health, rehabilitation, and education issues that impact independent living and self-determination realities for people with disabilities living in Indian Country.

2. Provide scheduled involvement for representatives of American Indian/Alaska Native (AI/AN) communities, advocates, and key organizations concerned with issues of education, rehabilitation, health, and independent living, as project advisors.

3. Identify and recommend basic factors/elements and key processes that have been productive in getting sovereign governments to develop tribal laws to protect and meet the service needs of people with disabilities who live in Indian Country.

4. Provide a capacity-building toolkit that is user friendly, incorporates principles of cultural competency, and includes as examples for consideration what seems to be working/what has been effective in different tribal settings.

5. Assess and recommend government-to-government (state to sovereign tribal to U.S. government) improvements in relationships needed for effective coordination across existing federally funded projects/programs.

6. Plan to broadly disseminate the project materials among Native people.

Method

This aggressive seven-month project inquired into the needs and issues facing people with disabilities in AI/AN communities as they affect education, health care, vocational rehabilitation, and independent living. A review of relevant literature and research findings was conducted. A 15-member Technical Expert Panel (TEP) was identified[2] and convened for three meetings at different points of the project. The TEP proved to be a solid foundation for this effort, providing ongoing advice and guidance. In addition, a tribal and disability community consultant provided

[2] The TEP members are identified in Appendix A of this report.

input during the course of the project. Headquarters and regional federal officials were identified and interviewed to discern their perspectives on opportunities for and barriers to realizing improved government-to-government relationships with sovereign tribal governments in meeting the service needs of tribal members and descendants with disabilities. Finally, throughout this report and the Toolkit, the term "Indian Country" is used to indicate the federally recognized tribal lands across the United States.

Technical Expert Panel

Individuals representing consumers and advocates within the AI/AN disability community across the country were recommended to serve as members of a national TEP. Tribal leaders were also recruited for the TEP to serve as advisors, particularly in the government-to-government discourse. Members of the TEP functioned in project consultant and advisory roles throughout the course of the research, providing guidance on the direction of the project. The TEP was instrumental in providing input on plans, critical feedback, direction, and redirection of issues this project addressed. In addition, the TEP was utilized to identify sovereign tribal governments to be interviewed as potential case studies.

Project Strategy

The project objectives and tasks were implemented in three major phases. Phase I involved the gathering of preliminary data and information. This phase culminated with the first gathering of the multidisciplinary TEP in July 2002. Phase I also incorporated timelines to organize the project, finalize work plans and schedules, and receive initial project sanction from the TEP. Phase II efforts centered on the collection of data, information, and input. This phase represented the substantive bulk of work for this project. It included finalizing the literature and research reviews, concluding the key respondent interviews, concluding the case studies, and concluding the consumer and tribal leader focus groups. Phase III provided a final feedback loop for the content of the deliverables through the TEP. Each of these three major phases required a strategy that built upon the development of relationships within the AI/AN communities, especially as the strategy relates to tribal members and descendants with disabilities and communication with tribal leadership.

Literature Review

The literature review and synthesis provided a foundation of information for defining key issues and for the design and conduct of the approach to the key respondent interviews and case studies. In addition, the findings were shared with the TEP for review, discussion, and suggestions for revision.

The approach to this task was designed broadly to identify, obtain, and assess published and unpublished information that provided insights into the nature of barriers to access to services in Indian Country, and the factors that may be associated with greater or lesser degrees of difficulties in obtaining supports and services in Indian Country.

Based on the preliminary literature review conducted as background for the initial project proposal, it was anticipated that standard literature search techniques would produce sparse data on barriers to access and on effective strategies for increasing access to services for the population of interest. Consequently, the supplementary activities included

- Search of Internet Web sites to identify organizations that serve or advocate for people with disabilities who live in Indian Country and to identify background papers, issue papers, data sources, projects, and studies that have addressed the relevant issues for this project.

- Telephone interviews with researchers who have been involved in studies of AI/AN health issues, to identify past and ongoing research projects and findings that may be relevant to this study.

- Telephone interviews with Federal Government employees in agencies that have responsibilities for health, education, vocational rehabilitation, independent living, and other services provided to people in Indian Country, to identify relevant data sources, studies, and initiatives for this study.

- Search of national databases (e.g., National Health Interview Survey, Medicare Current Beneficiary Survey, National Medical Expenditure Survey, Current

Population Survey, 1990 census, and 2000 census) and publications of data summaries from these surveys to obtain estimates of the number of people with disabilities in Indian Country and prevalence of each type of disability.

The first step in the literature survey was to conduct a search of published literature through standard literature sources, including

- Medline
- MedlinePlus: AI/AN Health
- Native Health Research Database
- Native Health History Database
- Education Resources Information Center
- www.disabilityresources.org/Native

These sources enabled identification of relevant published literature, from which a comprehensive bibliography was compiled and organized according to key topic areas. Brief abstracts of each publication were prepared from relevant and available full text. References cited in each publication were also searched to identify additional relevant literature.

Once the published literature bibliography was compiled, the search was expanded to Web sites of national Indian organizations concerned with health and social service issues, as well as organizations specifically focused on serving and advocating on behalf of AI/AN people with disabilities. These organizations included

- National Council of American Indians
- National Indian Health Board
- National Indian Council on Aging
- Association of American Indian Physicians
- American Indian Rehabilitation Research and Training Center (AIRRTC)

- National Center for American Indian and Alaska Native Mental Health Research, University of Colorado Health Sciences Center
- The Native Elder Health Care Resource Center, University of Colorado Health Sciences Center
- Rural Institute on Disabilities and American Indian Disability Technical Assistance Center (AIDTAC), University of Montana
- Native American Research & Training Center, University of Arizona
- Vocational Rehabilitation Service Projects for American Indians with Disabilities (Rehabilitation Services Administration Programs)

In addition, a search[3] of relevant Federal Government Web sites included

- Indian Health Service (IHS)
- Administration for Native Americans
- Administration on Aging
- Department of Education
- Department of Labor
- National Institutes of Health, including National Institute on Aging, National Institute on Alcohol Abuse and Alcoholism, National Institute of Mental Health, National

[3] A search of the U.S. Department of the Interior's Bureau of Indian Affairs Web site was not possible because of the temporary closing due to judicial order. Some BIA data were available at Project HOPE from other project work. During the next stage of this literature review task, contact and interviews with BIA staff were used to obtain additional information on relevant topics.

Institute on Deafness and Communication Disorders, National Institute of Diabetes and Digestive and Kidney Diseases, and National Institute on Drug Abuse

- Centers for Medicare and Medicaid Services
- Agency for Healthcare Research and Quality

After all the literature and interview results were synthesized by topic area with key findings highlighted, each topic area was then reviewed for completeness and gaps in information and research. The questions to be addressed in this review included the following:

1. What do we know with reasonable certainty, based on valid and reliable research?
2. What do the research findings suggest, for which supporting evidence is weaker?
3. What important issues, in this area, have not been addressed by any research?
4. What are the reasons that these issues have not been addressed (e.g., lack of appropriate data)?

The review includes a summary of findings from the literature, identification of gaps in the research and findings, and suggestions that could address these gaps in information and research.

Definition and Description of the American Indian and Alaska Native Population Living in Indian Country Overall, People with Disabilities, and Types of Disabilities

According to the 2000 U.S. Census, nearly 2.5 million Americans, or 0.9 percent of the U.S. population, identified themselves as American Indians or Alaska Natives. Approximately 4.1 million people or 1.5 percent of the U.S. population identified themselves as AI/AN or AI/AN in combination with another race. Of the people who indicated that they were AI/AN in combination with another race, the majority (66 percent) identified the other race as "White."

In 1990, the population of AI/AN was approximated at 1.9 million.[4] Although comparison of the 1990 and 2000 census data suggests a 10-year increase in the AI/AN population, the actual magnitude of this increase is unclear because of changes in how the census collects and reports information on race. Specifically, the 1990 census required people to affiliate with only one racial group, and the 2000 census allowed people to identify with multiple racial groups. Comparison of the 1990 AI/AN population estimates to the population who indicated that they were AI/AN in 2000 shows a rate of increase of 26 percent. However, comparison to the total number of people who identify their race as AI/AN only or AI/AN in combination with other races shows a 10-year increase of 110 percent. In contrast, the population of the rest of the United States (all races) increased by only 13 percent during that same period (U.S. Census, 2000).

Population Off and On the Reservation

Although American Indians and Alaska Natives reside in all states of the United States, approximately 42 percent of the AI/AN population (one race only) living both on and off reservations are located in four states: Arizona, California, New Mexico, and Oklahoma.[5] Nearly one-half of the AI/AN population reside in the Western United States, compared with 30 percent who reside in the South, 16 percent who reside in the Midwest, and less than 7 percent who reside in the Northeast.

Defining Indian Country: The Census Bureau distinguishes several types of tribal lands. Federally recognized reservations and off-reservation trust lands are those geographic areas to which the Federal Government has granted sovereignty and whose tribal members are eligible to receive services from the U.S. Department of the Interior's Bureau of Indian Affairs (BIA). Indian tribes with or without a land base may also be recognized by individual states but not by the U.S. Department of the Interior. In the latter case, the census considered tribal members to be

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[4] The number of American Indians reported in 1990 is believed to understate the actual number of Indians residing in the United States. Census takers are believed to have undercounted the number of Indians residing on reservations by more than 12 percent. (Richardson D, *Bureau of Labor Statistics Daily Report*, December 28, 1999.)

[5] U.S. Census Bureau, "The American Indian and Alaska Native Population: 2000," *Census 2000 Brief*, February 2002.

residing in a state-designated American Indian statistical area. In some cases, an American Indian population that resides within a geographic area may function as an organized tribe but not be recognized by either the state or the Federal Government. These distinctions across American Indian lands are important in understanding barriers to access to health and social services that people with disabilities face, because it is only on federally recognized tribal lands that the tribal jurisdiction is granted sovereignty. As such, it is only on federally recognized reservations where the benefits afforded to people with disabilities through the Americans with Disabilities Act (ADA) are not consistently ensured. The matter of this exemption is discussed later in this report.

Approximately 944,433 people resided on federal reservation and off-reservation trust land in 2000. States with the largest population on federally recognized reservations are Arizona, New Mexico, and Washington. These three states are home to nearly one-half of the U.S. populations who live on federal reservations. It is important to note that the number of American Indians and Alaska Natives that are currently living on or near reservations is expected to be somewhat less since these figures include people of all races and ethnicities.[6] In fact, less than one-third of people who identified themselves as AI/AN in the census and one-fifth of people who identified themselves as either AI/AN or AI/AN in combination with another race resided on a federally recognized reservation in 2000.[7]

BIA officially recognizes over 560 tribes. The 10 largest tribal groupings in the United States are the Cherokee, Navajo, Latin American Indian, Choctaw, Sioux, Chippewa, Apache, Blackfeet, Iroquois, and Pueblo. Two-thirds of all people who specified a tribal affiliation on the 2000 census identified themselves as Cherokee either in whole or in combination with another tribal

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[6] For example, only 15 percent of the population residing in the Southern Ute Reservation of Colorado in 2000 indicated that they were entirely American Indian or American Indian in combination with another race. Similarly, according to the census, only 35 percent of the population of the Lake Traverse Reservation of South Dakota self-identified themselves as American Indian. The majority of the population on both these reservations identified themselves as "White."

[7] Personal conversation with Jackie Kruszek, Office of Native American Programs, Denver National Program Office, June 20, 2000.

group. One-fourth self-identified with the Navajo Tribe. Among Alaska Natives, the largest tribal group is the Eskimo.[8]

Disability Prevalence Among American Indians and Alaska Natives

It is important to note that statistics vary, depending on the source of data and the definition of disability. The numbers also vary according to the type and severity of the disabilities included. There continue to be problems with widely used disability employment and other data in U.S. Census 2000, including concern about the inadequate collection and analysis of relevant and reliable statistical data on America's population with disabilities.

NCD recognizes that findings of the 2000 census, together with those of other compilations relating to the employment status of Americans with disabilities, are being severely questioned on methodological and validity grounds. The accuracy of this data is critically important in an era of evidence-based policy because misleading information can lead to misguided or premature public policy decisions.

Data from the 1997 Survey of Income and Program Participation (SIPP) indicates that nearly 20 percent of the U.S. population has some level of disability. Twelve percent of the population had a developmental or other disability of sufficient severity to require the use of a wheelchair, cane, or crutches and to prevent them from working, or for which they required assistance in performing activities of daily living or instrumental activities of daily living.[9] The prevalence of disabilities has been found to vary significantly by racial and ethnic group. In 1991–1992, nearly 20 percent of Whites and Blacks were estimated to have a disability (defined as the presence of one or more functional limitations) compared with 15 percent of Hispanics and 10 percent of Asian and Pacific Islanders. According to the SIPP, rates of disability were highest among American Indians and Alaska Natives; nearly 22 percent of American Indians, Eskimos, and

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[8] Ogunwole S, "The American Indian and Alaska Native Population: 2000," *Census 2000 Brief*, February 2002.

[9] McNeil J, "Americans with Disabilities 1997," *Current Population Reports*, U.S. Census Bureau, February 2001.

Aleuts were estimated to have a disability. Rates of disability were even higher among the working age population. Nearly 27 percent of American Indians and Alaska Natives between the ages of 16 and 64 were estimated to have a disability in 1991–1992.[10]

The state-specific estimates from 1990 U.S. Census data on American Indians and Alaska Natives (living both on and off reservations) with a disability reveal that rates of disability vary substantially across states. With few exceptions, rates of disabilities in the AI/AN population tend to be higher in southern states compared with rates in Arizona, New Mexico, and Utah. Among working age AI/AN adults (ages 16 to 64), rates of disability range from a high of over 25 percent in the states of Kentucky, Mississippi, and West Virginia to a low of approximately 12 percent in the states of Alaska, North Dakota, and Wyoming. Rates of disability also vary significantly among the elderly AI/AN population, from a low of 16 percent in Wyoming to a high of nearly 41 percent in Mississippi.

Reservation-specific estimates of disability, for reservations with more than 5,000 persons, are also provided in the 2000 census for the states of California, Arizona, Washington, New Mexico, Montana, and South Dakota. These estimates are based upon a sample of the population. Estimates may therefore be unreliable because of the small number of American Indians and Alaska Natives from any reservation included in the samples. Nevertheless, this data may suggest trends in the prevalence of disability across tribal groups that should be further investigated.

There is a three-fold difference in the proportions of children with disabilities residing in these reservations sampled in the six states listed in the previous paragraph. Approximately 3.4 percent of children living on the Hopi Reservation in Arizona are estimated to have a disability compared with over 10 percent of children in the Tohono O'odham Reservation in Arizona. Rates of disability were not only higher among adults but also varied widely, from a low of 13.5 percent in the Port Madison (WA) Reservation to a high of over 37 percent in the Fort Apache (AZ) and Salt River (AZ) Reservations. Estimated rates of disability among senior citizens living on

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[10] Bradsher J, "Disability among Racial and Ethnic Groups," Disability Statistics Center, January 1996.

reservations are, in many cases, dramatically high. Nearly three-quarters of residents over the age of 65 in the Fort Apache (AZ), Gila River (AZ), Hopi (AZ), Navajo (AZ), and Zuni (NM) reservations are estimated to have a disability.

The extent to which variation in disabilities across reservations is attributable to difference in the proportion of American Indians (as opposed to people of other racial groups) who are living on these reservations is unclear.

Types of Disabilities

Information on the types of disabling conditions that are most prevalent on Indian reservations is limited to a small number of studies that either have surveyed organizations serving American Indians and Alaska Natives (e.g., tribal representatives, independent living centers) or have analyzed administrative data. In 1994 the American Indian Disability Legislation Project conducted a survey of 143 AI/AN tribes to obtain information on the accessibility of public buildings, availability of rehabilitation services, and tribal awareness of disability laws. Surveyed tribes were also asked to report on the frequency of disabling conditions. The disabilities most frequently cited by tribes in the continental United States were diabetes (29 percent), emotional disabilities (22 percent), and learning disabilities (11 percent). Among tribes in Alaska, emotional disabilities (31.3 percent), learning disabilities (17 percent), and deafness or hardness of hearing (17 percent) were the most frequently reported disabling conditions.[11]

Clay (1992) conducted a survey of independent living centers (ILCs) to identify the services that are available to American Indians residing on reservations. According to 42 ILCs that indicated that they served people on reservations or tribal lands, the most frequently observed disabilities among American Indians living on reservations were spinal cord injury, diabetes, blindness,

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[11] Fowler L, Seeking T, Dwyer K, Duffy SW, Brod RL, Locust C, "American Indian Disability Legislation and Programs: Findings of the First National Survey of Tribal Governments," *Journal of Disability Policy Studies* 10(2):166–185.

mobility disability, traumatic brain injury, deafness, hardness of hearing, orthopedic conditions, and arthralgia. Rates of each of these disabilities were not provided.[12]

AIRRTC also examined the prevalence of different types of disabilities among American Indians using data from administrative files maintained by the U.S. Department of Education's Rehabilitation Services Administration (RSA). Since the RSA files contain information on people who have undergone rehabilitation, estimates of the prevalence of disabling conditions may not be representative of the AI/AN population; rather, estimates of disabling conditions derived from this data are likely to reflect the characteristics of people who utilized these services. Nonetheless, this data is useful for purposes of comparing the prevalence of disabling conditions among AI/ANs to that of other racial groups.

AIRRTC analyses found that alcohol abuse or dependence was the most common cause of disability among American Indians and Alaska Natives represented in the 1997 RSA database. Approximately 11 percent of AI/AN clients had a major diagnosis of alcohol abuse compared with only 4 percent of White, nearly 6 percent of Black, and less than 2 percent of Asian clients. Although the prevalence did not vary substantially by race, learning disabilities were found to be the second most frequent major diagnosis (9 percent) among AI/AN clients represented in the RSA database. The frequency of sensory disabilities, however, tended to be slightly lower among American Indians and Alaska Natives than other racial groups. Among AI/AN clients, 1 percent were blind/low vision and 0.8 percent were deaf/hard of hearing compared with 1.9 percent and 1.24 percent, respectively, of the total in the RSA database.[13]

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[12] Clay J, *A Profile of Independent Living Services for American Indians with Disabilities Living on Reservations*, University of Montana Rural Institute, Missoula, MT, 1992.

[13] Schacht R, Gahungu A, White M, LaPlante M, and Menz F, *An Analysis of Disability and Employment Outcome Data for American Indians and Alaska Natives*, American Indian Rehabilitation Research and Training Center, Flagstaff, AZ, September 2000.

Unique Legal, Environmental, and Economic Factors Affecting Provision of and Access to Appropriate Services for People with Disabilities in Indian Country

Compared with other U.S. citizens, American Indians and Alaska Natives living in Indian Country have a unique legal status that affects the protections and services available to people with disabilities living on these lands. The definition of Indian Country is derived from 18 U.S.C. Subsection 1151. Although Subsection 1151 is in the criminal code, this section has been applied in civil cases as well. Subsection 1151 provides that "Indian Country" means

> (a) all land within the limits of any Indian reservation under the jurisdiction of the United States Government, notwithstanding the issuance of any patent, and, including rights-of-way running through the reservation, (b) all dependent Indian communities within the borders of the United States whether within the original or subsequently acquired territory thereof, and whether within or without the limits of a state, and (c) all Indian allotments, the Indian titles to which have not been extinguished, including rights-of-way running through the same.[14]

Indian Country, in both civil and criminal matters, is subject to the jurisdiction of tribal governments.[15]

In addition to the unique legal status of AI/AN residents, Indian Country is disproportionately rural or frontier. This poses a number of logistical and resource challenges to provision of and access to social, health, and support services. Historically, American Indians and Alaska Natives tend to have less education, less employment, and lower incomes than other people in the United States and, thus, tend to have fewer resources to address the needs of people with disabilities.

Environmental Factors

Most of Indian Country is located in rural and frontier areas in the United States, and American Indians and Alaska Natives are more likely than any other racial group to reside in

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[14] 18 U.S.C. § 1151.

[15] See, e.g., *DeCoteau v. District County Court*, 420 U.S. 425 (1975).

nonmetropolitan areas.[16] While the challenges of providing services to people with disabilities in rural/frontier areas are not unique to American Indians and Alaska Natives, the substantial majority of people with disabilities in Indian Country are located in rural/frontier areas. People living in rural areas generally experience barriers to accessing health care and other social services; people with disabilities in rural areas face even greater barriers in obtaining the complex medical and related services that they require.[17]

Barriers to health care access and other services in rural areas include lack of resources, long travel distances, and lack of transportation. In addition, people from diverse cultures in rural areas often experience cultural and language barriers to obtaining appropriate health care. They seldom encounter health care and other service providers of the same cultural backgrounds or who have been educated to provide services in a culturally appropriate manner.[18]

NCD has identified a number of challenges in obtaining necessary services faced by people with disabilities from diverse cultures and by people with disabilities in rural areas, including lack of resources and lack of education and training on policy, cultural issues, services, and attitudes.[19] Thus, American Indians and Alaska Natives with disabilities residing in rural Indian Country are dually challenged in their efforts to obtain appropriate services and support.

Economic Factors

American Indians and Alaska Natives, particularly those living in Indian Country, face significant economic challenges. National data shows that in 1990, 78 percent of Whites had

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[16] Snipp C, "Selected Demographic Characteristics of Indians," in *American Indian Health: Innovations in Health Care, Promotion, and Policy* (ed. by ER Rhoades), The Johns Hopkins University Press, Baltimore, MD, 2000.

[17] Lishner D, et al., "Access to Primary Health Care Among Persons with Disabilities in Rural Areas: A Summary of the Literature," *Journal of Rural Health*, Winter 1996; 12(1): 45-53.

[18] Mueller K, et al., "Health Status and Access to Care among Rural Minorities," *Journal of Health Care for the Poor and Underserved*, May 1999; 10(2): 230-249.

[19] National Council on Disability, *Outreach to Minorities with Disabilities and People with Disabilities in Rural Communities: Roundtable Report on Findings*, Atlanta, Georgia, August 4, 1997.

completed high school and 22 percent had completed a college degree; AI/AN rates compared at 65 percent and 9 percent, respectively.[20] Lower educational levels are associated with reduced income potential, and AI/AN household and family income levels in 1989 were approximately 60 percent of White household and family income.

People who live in Indian Country are more likely than all American Indians and Alaska Natives to be very poor and unemployed. BIA data indicates that in 1999, approximately 50 percent of American Indians and Alaska Natives who were members of a federally recognized tribe living on tribal lands were either unemployed or employed with household incomes below the federal poverty levels.[21]

Poverty, unemployment, low levels of education, inadequate housing and sanitation, and inadequate funding for federal health and other programs responsible for providing services to American Indians and Alaska Natives in Indian Country are all current problems in Indian Country. These problems contribute to the poor health status of American Indians and Alaska Natives. These problems also contribute to a lack of services to meet health care and social service needs of all people residing in Indian Country, particularly those people with disabilities.

Understanding Government-to-Government Relationships

Despite representing a small percentage of the total U.S. population, American Indians and Alaska Natives enjoy a unique legal, historical, and political relationship with the Federal Government. As indigenous peoples, Indian tribes engaged in government-to-government relationships with other sovereign countries before the United States was established.[22] At its formation, the United States recognized the unique relationship with Indian tribes, and this

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[20] Snipp C, "Selected Demographic Characteristics of Indians," in *American Indian Health: Innovations in Health Care, Promotion, and Policy* (ed. by ER Rhoades), The Johns Hopkins University Press, Baltimore, MD, 2000.

[21] Barents Group of KPMG Consulting, Inc., *American Indian/Alaska Native Eligibility and Enrollment in Medicaid, SCHIP, and Medicare: Design Report*, prepared for Centers for Medicare and Medicaid Services, April 11, 2002.

[22] See, e.g., *Montoya v. United States*, 180 U.S. 261 (1901).

recognition continues today. The Federal Government recognizes tribes as "domestic dependant nations."[23]

To further this government-to-government relationship, in 2000, the Federal Government announced a policy of consultation with tribal governments in Executive Order #13175.[24] The Executive Order requires meaningful consultation with tribal officials on any regulatory policies that have tribal implications. Federal agencies are required to consult with tribes during the development of new policies. When possible, federal agencies must grant tribes the maximum administrative discretion possible. Agencies are required to consult with tribes when developing federal standards. They must also encourage tribes to formulate and implement their own policies and establish standards. This Executive Order was reconfirmed recently by the Honorable Alberto R. Gonzales, Counsel to the President, in a letter to Congressman Frank Pallone dated June 25, 2002.[25] Subsequently, Congressman Frank Pallone issued a letter to advocates of Indian Country quoting Mr. Gonzales and stating his own commitment to Executive Order #13175.[26]

Legal Factors

Individuals with disabilities living in Indian Country face a complex legal environment. Long recognized as distinct political entities,[27] Indian tribes enjoy the "inherent powers of a limited sovereignty which has never been extinguished."[28] Indian tribes are protected from private

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[23] *Cherokee Nation v. Georgia*, 33 U.S. 1, 33 (1831).

[24] Executive Order #13175 of November 6, 2000.

[25] Reconfirmation of Executive Order #13175 of June 19, 2002. Official White House correspondence from Alberto Gonzales, Counsel to the President, to Congressman Frank Pallone, Jr.

[26] Reconfirmation of Executive Order #13175 of June 19, 2002. Official Correspondence from Congressman Frank Pallone to Advocates of Indian Country. June 25, 2002.

[27] *Worcester v. Georgia*, 31 U.S. 515, 559 (1832).

[28] *United States v. Wheeler*, 435 U.S. 313, 322 (1978).

lawsuits under the doctrine of sovereign immunity.[29] As a result of tribal sovereign immunity to suit, not all federal regulations that apply in Indian Country are enforceable by private parties against tribes.

A tribe is subject to suit by a private party under these laws only when the tribe has expressly waived its sovereign immunity. Thus, individuals with disabilities concerned about their rights and protections guaranteed under the Rehabilitation Act or ADA may face unique barriers when seeking enforcement by a tribal government. Recent decisions in the Eleventh Circuit suggest that while tribes are not specifically excluded from the provisions/requirements and protections of the Rehabilitation Act of 1973[30] and the Americans with Disabilities Act of 1992,[31] enforcement may be limited.[32]

Title I of the Americans with Disabilities Act and Tribes

In passing ADA, Congress announced the purpose as providing "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."[33] Title I of ADA requires that employers with 15 or more employees provide qualified individuals who have a disability with an equal opportunity to benefit from the full range of employment benefits available to others. Title I also restricts discrimination in hiring, promotions, pay, and other privileges of employment. Employers must make reasonable accommodation for the known physical or mental disability of otherwise qualified individuals with disabilities, unless it results

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[29] See, e.g., *Kiowa Tribe of Oklahoma v. Manufacturing Technologies Inc.*, 523 U.S. 749 (1998) (holding that, with regard to suits brought by private parties against Indian tribes, "s a matter of federal law, a tribe is subject to suit only where Congress has authorized the suit or the tribe has waived its immunity").

[30] Rehabilitation Act of 1973, 29 U.S.C. §§ 701 et seq.

[31] Americans with Disabilities Act, 42 U.S.C. §§ 12101 et seq.

[32] See *Florida Paraplegic Association, Inc. v. Miccosukee Tribe of Indians of Florida*, 166 F.3d 1126 (11th Cir. 1999); *Sanderlin v. Seminole Tribe*, 243 F.3d 1282 (11th Cir. 2001).

[33] 42 U.S.C. § 12101(b)(1).

in an undue hardship. While Title I categorically excludes tribal governments as employers under this title, ADA does not exclude qualifying private employers operating in Indian Country.[34]

Title II of the Americans with Disabilities Act

ADA did not include an explicit exemption for tribal governments under Title II as it did in Title I. On June 22, 1999, the Supreme Court decided a landmark ruling interpreting Title II. In *Olmstead v. L.C.*, the Supreme Court held that Title II of ADA requires states to provide community-based treatment for persons with mental disabilities when the state's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated.[35] When considering whether the placement can be reasonably accommodated, it is necessary to consider the resources available to the state and the needs of others with mental disabilities. The practical application of this ruling is that states must help to provide the least restrictive level of care for people with disabilities, moving away from institutionalization and toward home- and community-based care. This ruling could present new opportunities for tribal governments to develop home- and community-based services that are reimbursed by Medicaid or other sources.

Title III of the Americans with Disabilities Act and Tribes

Title III of ADA prohibits discrimination in public accommodations. A case involving public accommodations for people with disabilities at a tribal facility provides some insight. On the basis of Congress' intent to end discrimination and the statute's broad language, the Eleventh Circuit has ruled that Title III of ADA does apply to tribes.[36]

However, a federal court finding that a statute is applicable to a tribe is not the same as finding a waiver of tribal sovereign immunity.[37] While Title III of ADA may apply to tribes, the Eleventh

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[34] 42 U.S.C. § 12111(5)(B)(i).

[35] *Olmstead v. L.C.*, 527 U.S. 581 (1999).

[36] *Florida Paraplegic Association, Inc. v. Miccosukee Tribe of Indians of Florida*, 166 F.3d 1126 (11th Cir. 1999).

[37] *Ibid.*

Circuit found that the sovereign immunity of tribal governments prohibits private suits for enforcement against tribes in federal courts. In such cases, individuals with disabilities may have a right without a remedy.

Title III does provide for suits brought for enforcement by the U.S. Department of Justice.[38] While this possibility exists, no such action has been brought by the Department of Justice to date. It is also important to note that this ruling of the Eleventh Circuit was not taken to the U.S. Supreme Court.

The Rehabilitation Act and Tribes

The Rehabilitation Act prohibits discrimination based on disability in programs conducted by federal agencies, including programs receiving federal funds and in federal employment. In determining employment discrimination, the Rehabilitation Act uses the same standards as Title I of ADA.

Section 121 of the Rehabilitation Act authorizes RSA to make grants to tribes for the purpose of vocational rehabilitation (VR) services. Tribes accepting these grants, and generally other federal funds, agree to comply with federal law. However, this agreement may not amount to a waiver of sovereign immunity, which protects tribes from suit in federal court.[39]

The Individuals with Disabilities Education Act and Tribes

The purpose of the Individuals with Disabilities Education Act (IDEA) is to ensure that every child has available a free, appropriate public education that meets individual needs.[40] IDEA intends to improve the educational results of children with disabilities. To reach this goal, IDEA requires (1) an Individualized Family Service Plan (IFSP) for infants and toddlers with developmental delays, and (2) an Individualized Education Program (IEP), developed by the

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[38] *Ibid.*

[39] *Sanderlin v. Seminole Tribe*, 243 F.3d 1282 (11th Cir. 2001); but cf. *Cruz v. Ysleta Del Sur Tribal Council*, 842 F. Supp. 934 (W.D. Texas 1993) (order dismissing Tribe's motion to dismiss because of sovereign immunity).

[40] 20 U.S.C. § 1400(d)(1)(A).

IFSP or IEP team, which includes parents and others as decisionmakers, for each eligible child of school age with a disability.

To assist in meeting needs of children and families in Indian Country and in Department of the Interior-funded schools, IDEA provides a set-aside or percentage of funds from the U.S. Secretary of Education to the Secretary of the Department of the Interior. IDEA funds for infants and toddlers (ages 0–3) are provided directly to tribes by the Department of the Interior. Until the late 1990s, the tribes were not contacted directly by the Department of Education and asked to account for how needs were met for children with disabilities and their families. While IDEA calls for states to provide services to all children of preschool age eligible under IDEA, many children ages 3 to 5 in Indian Country face difficulty in receiving any support from state agencies. Thus, many children often fall through the cracks until they are five years old and can be served by either public or BIA-funded schools.

IDEA provides that the Secretary of the Department of the Interior receive funds from the Secretary of Education to educate children ages 5 to 21 with disabilities on reservations in elementary and secondary schools operated and funded by the Secretary of the Interior.[41] The IDEA also provides an administrative enforcement process that the BIA-funded schools are subject to, based upon their status as a local educational agency.[42] However, IDEA does not waive tribal sovereign immunity because the federal law does not contain the explicit, unequivocal waiver that is necessary. While the U.S. Department of Education has the authority to withhold federal funding when the BIA-funded schools have been out of compliance in meeting children's needs and in protecting families under IDEA, as well as in failing to improve physical accessibility of BIA facilities, this sanction has not been applied. The investigation for this NCD project revealed concern at the local level regarding adequate federal funding to ensure the BIA's ability to meet its mandates under IDEA. Advocacy by parents and other groups is critical to protect the rights of Indian children with disabilities, whether in BIA-funded or public schools.

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[41] 20 U.S.C. § 1411(i)(1)(A).

[42] 20 U.S.C. § 1401(15(C).

Advocacy Options

The outcomes above may suggest that along with states where tribal lands are located, some tribal governments are failing to meet their responsibility to individuals with disabilities. For many tribes, current funds may be inadequate to address all of the needs of people with disabilities, including improving accessibility in Indian Country. Although, entangled in this complex legal environment, individuals with disabilities living in Indian Country have potential options. A tribe could waive its sovereign immunity to allow suits brought under ADA in federal courts. A more likely scenario might be an increase in the number of tribal governments passing ordinances providing protections similar to those in federal statutes, such as ADA or the Rehabilitation Act. A tribe could thus provide a legal remedy within the existing tribal legal system through a limited waiver of sovereign immunity. Tribal governments have the inherent authority to pass laws, develop programs, and ensure protection and accessibility for people with disabilities under their jurisdiction. A recent survey conducted by the American Disability Legislation Project found that "schools, stores, churches, Bureau of Indian Affairs and other federal buildings, and tribal courts and jail facilities were accessible about two-thirds of the time" (p. 2). Other major tribal facilities, such as health centers and senior citizen buildings, were found to be accessible about 75 percent of the time. Similarly, most major services for people with disabilities were accessible about 71 percent of the time.[43] However, this report also notes that only 13 percent of tribes had a line item in their budget for disability issues. The political power of people with disabilities, their families, and advocates could help to move tribal governments toward adopting such ordinances.

The doctrine of tribal sovereign immunity from suit in federal court does not necessarily support the proposition that the requirements of ADA are inapplicable to tribal governments in all circumstances. In drafting ADA, Congress makes it clear that the act is a "national mandate" to end discrimination. Furthermore, the Act and other comparable legislation suggest that Indian tribes should be the recipients of grants to ensure compliance. If tribes are to meet these federal requirements, increased funds are necessary. Currently, a policy paradox exists in which AI/AN

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[43] Fowler L, Seeking T, Dwyer K, Duffy SW, Brod RL, Locust C, "American Indian Disability Legislation and Programs: Findings of the First National Survey of Tribal Governments," *Journal of Disability Policy Studies* 10(2):166–185.

people with disabilities, caught between the doctrine of tribal sovereign immunity and a national policy to end discrimination, suffer the consequences.

Despite the legal challenges for enforcement of ADA and related legislation in Indian Country, American Indians and Alaska Natives have a unique relationship with the Federal Government that promises federally provided health, education, and social services. To uphold this promise, the Federal Government could provide appropriate services and support for people with disabilities in Indian Country. Pursuant to trust responsibility of the Federal Government to Indian tribes, federal agencies are responsible for carrying out these guarantees. However, funding for these programs has been inadequate to effectively address the needs of people with disabilities in Indian Country.

In addition, the complex and conflicting structure of federal responsibilities for services provided to American Indians and Alaska Natives results in jurisdictional conflicts, both intra-agency and inter-agency. Such conflicts may lead to a lack of accountability and inadequate or no services provided to people with disabilities in Indian Country. For example, 10 years ago a National Indian Justice Center report suggested that the Department of Education assign to BIA exclusive responsibility for Indian children on reservations that have BIA schools. However, in light of the fact that the overwhelming majority of AI/AN children are educated in public schools, BIA believed it was responsible only for those children enrolled in its programs.[44] The authors of the report also note that multiple organizations with roles in developing and delivering services to American Indians and Alaska Natives with disabilities have led to "interagency competition and conflict, jurisdictional confusion, and 'passing the buck'."[45]

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[44] National Indian Justice Center, *Disabilities and Their Effects on American Indian and Alaska Native Communities: Final Report on Roundtable Conference*, December 12–13, 1991, Department of Health and Human Services, Public Health Service, Indian Health Service, Rockville, MD, 1992.

[45] *Ibid.*, p. 2.

Barriers to Provision of and Access to Appropriate Services for People with Disabilities in Indian Country

> *"People have ideas about disabilities but they don't know what it's like. They might want to hold you back. I still have all the mechanical knowledge from running heavy equipment but just because I can't do that anymore, I can still do things like change the transmission on my car by myself."*
>
> *—Joseph Garcia, Prairie Band of Potawatomi*

General Barriers

In this section, general barriers common to people from diverse cultures and rural people with disabilities are discussed. Then specific barriers that are unique to people with disabilities in Indian Country are described.

While all people with disabilities may face a myriad of challenges in obtaining appropriate services to enable them to function effectively and productively, people who are members of diverse racial and ethnic populations and people with disabilities in rural areas may encounter even greater barriers to necessary supportive services and accommodation than do other people with disabilities. Recognizing the significant difficulties that may face people from diverse cultures who have disabilities and their unique needs, NCD developed a key initiative to address these needs.[46]

NCD has continued from 1993 to the present to focus attention on the need for special efforts to ensure that people with disabilities from diverse cultures are able to obtain necessary appropriate services and support. In the 1997 Roundtable Report of Findings, NCD noted that "there was consensus that the needs of [people] with disabilities and from [diverse cultures] and people with disabilities living in rural communities warrant ongoing corrective attention in all aspects of the fabric of American public policy" (NCD Roundtable Report, p. 2). In 1999, NCD summarized

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[46] National Council on Disability, *Meeting the Unique Needs of Minorities with Disabilities: A Report to the President and the Congress*, April 26, 1993. National Council on Disability, *Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation*, December 1, 1999. National Council on Disability, "Carrying on the Good Fight: Summary Paper from Think Tank 2000—Advancing the Civil and Human Rights of People with Disabilities from Diverse Cultures," August 23, 2000.

findings and recommendations for addressing barriers to access to services and support for people with disabilities from diverse cultures and their families.[47]

General barriers to access to necessary and appropriate services identified through the NCD meetings on consumers and advocates included

- Persistent lack of access to appropriate job training and employment opportunities
- Persistent lack of childcare and afterschool programs
- Greater difficulty gaining access to public accommodations (e.g., markets, restaurants) due to lesser compliance with ADA access mandates
- Greater difficulty gaining access to public transportation and greater unwillingness of public transportation personnel to accommodate people with disabilities who are also from diverse cultures
- Lack of culturally competent and culturally appropriate service delivery, including

  lack of people from diverse cultures in the disability service professions, particularly in rural areas

  inadequate culturally appropriate outreach to ensure that people are aware of services and resources that are available to them

  lack of bilingual speakers, interpreters, and language-appropriate communications materials

The digital divide or limited information technology infrastructure in rural areas poses another barrier to independent living for American Indians and Alaska Natives with disabilities. For

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[47] National Council on Disability, *Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation*, December 1, 1999. National Council on Disability, "Carrying on the Good Fight: Summary Paper from Think Tank 2000—Advancing the Civil and Human Rights of People with Disabilities from Diverse Cultures," August 23, 2000.

instance, approximately 24 percent of AI/AN households do not have telephones. Less than 30 percent of AI/AN households are equipped with a computer and less than 20 percent have Internet access.[48] In addition to these general barriers to access that are encountered by people with disabilities from diverse cultures, people in rural areas with disabilities also face additional barriers, including long distances to obtain services, lack of transportation and appropriate accommodation to travel to services, greater difficulty obtaining assistive technology or specialized equipment due to lack of commercial establishments with sufficient market demand, and lesser awareness of and/or lack of resources to provide accommodation to facilitate access to services in rural areas.

People with disabilities in Indian Country encounter these general barriers in common with other people from diverse cultures and rural people with disabilities. Since many tribal lands are in remote rural and frontier areas, the barriers that tribal members face may be more extreme on average than those faced by rural people with disabilities generally. Similarly, because the AI/AN population in Indian Country is less than 0.5 percent of the U.S. population, the lack of AI/AN disability service providers is likely to be more severe than for other culturally diverse populations. In addition, for people in Indian Country who speak a native language, appropriate interpreters and language-appropriate communications materials are even less likely to be available.

Over and above these general barriers to access to services, people with disabilities in Indian Country also face a number of additional uniquely difficult and challenging barriers.

Unique Barriers

People with disabilities in Indian Country reside in areas that pose special issues for obtaining access to services and accommodation to facilitate their full participation in society. These unique aspects of tribal lands include the following:

- Legislation mandating rights for people with disabilities is not automatically enforceable in Indian Country.

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[48] Davis T and Trebian M, "Shaping the Destiny of Native American People by Ending the Digital Divide," EDUCAUSE Review, January/February 2001: 38–46.

- Tribal leaders and communities lack awareness and adequate knowledge of programs to meet the needs of people with disabilities in Indian Country.

- A number of federal agencies have interrelated and conflicting responsibilities for provision of health, education, and social services in Indian Country that result in failure and lack of accountability to meet the needs of people with disabilities.

- Chronic underfunding of federal programs serving people in Indian Country results in inadequate and rationed services that do not meet the needs of all people in Indian Country, including those of people with disabilities.

- Indian Country, for the most part, is composed of small, isolated populations with limited resources and capabilities to develop and implement programs and accommodations for people with disabilities.

- Tribes are distinct groups, with different cultures, languages, and resources, and would likely require unique approaches to inform and facilitate changes to meet the needs of people with disabilities in Indian Country.

Disability Legislation in Indian Country

People with disabilities living in Indian Country may not be afforded the benefits and protections of ADA and other legislation affecting rights and services. Because of the unique relationship between tribal governments and the U.S. government, legislation that does not specifically address Indian tribes is generally assumed not to apply to tribal areas. For ADA (and other similar legislation) to apply to tribal lands, the Federal Government likely would need to conduct separate negotiations with each of the more than 500 federally recognized tribes.[49] A recent decision in the Eleventh Circuit Court suggests that while tribes are not specifically excluded, there is limited enforcement for ADA compliance. Like federal and state governments, tribes enjoy sovereign immunity from being sued unless the tribe allows for suit or Congress explicitly

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[49] American Indian Disability Legislation Project, *Findings of a National Survey of Tribal Governments*, Rural Institute on Disabilities, The University of Montana, December 1995.

provides for suits. Thus, enforcement of ADA in Indian Country would require that the Federal Government bring suit against the tribes or that Congress take explicit action to include tribes within the scope of ADA.

In the absence of legislative action or conduct of separate negotiations between the Federal Government and tribal governments, individuals with disabilities in Indian Country are limited to negotiation and political efforts to persuade tribal governments to adopt policies to ensure rights and provide accommodations.

A 1995 survey conducted by the American Disability Legislation Project found that at least one tribe has chosen to adopt ADA as a whole through tribal resolution and is now sorting out what this means for its members. In addition, AIDLP reported that several tribes had passed resolutions that deal with employment of people with disabilities, one tribe had created an Office of Special Education to ensure that tribal children with disabilities would have their educational needs met, and other tribes had taken steps to begin addressing issues for meeting the needs of people with disabilities. At the same time, the AIDLP survey revealed that only 13 percent of responding tribes had at least one line item in their budget related to disability services; however, the average amount per tribe for these line items was very small (e.g., an average amount of $5,033 for staff training on disability issues and $12,500 for employment services for people with disabilities).

Lack of Awareness/Adequate Knowledge

The AIDLP survey of American Indian tribes indicated that only 37 percent of respondents reported that their tribe was familiar with ADA, the relevant sections of the Rehabilitation Act, or IDEA. Only 6 percent indicated that their tribal governments were very familiar with major disability legislation. None of the Alaska Native respondents stated that their tribal governments were very familiar with major disability legislation. Of American Indian respondents, 74 percent said that they believed that their tribal government would be interested in participating as a focus group for establishing disability legislation within their tribe (NCD Roundtable Report, p. 23).[50]

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[50] *Ibid.*

Most respondents to the survey indicated that it was very important that tribal members with disabilities be treated with respect.

Complex and Interrelated Federal Agency Responsibilities

A wide variety of federal agencies have some level of responsibility for providing services for people with disabilities in Indian Country. However, it has never been clearly delineated which agencies are specifically accountable for providing specific services. As a result, many services may be provided on a piecemeal basis or not at all, even when there are clear federal responsibilities under law and treaty agreements. The U.S. Department of Health and Human Services' (HHS) IHS, the U.S. Department of the Interior's BIA, and the U.S. Department of Education's Office of Special Education Programs and RSA all have some role in developing and delivering services to AI/AN people with disabilities in Indian Country. However, a 1991 report states, "There are disagreements about who is primarily responsible for providing services to Indian children with disabilities."[51] The authors go on to note that "'jurisdictional confusion and 'passing the buck'...have impeded delivery of services to people with disabilities. This lack of coordination needs to be remedied at federal and state levels to ensure efficient delivery of services...."[52] This same study notes that American Indian children received special education from a variety of sources including BIA, Head Start, IHS, and local public school districts. However, less than 30 percent of those in need of special education services received some services and, of those, about one quarter received fewer services than prescribed by their IEP.

Inadequate Funding of Federal Agencies with Responsibilities for Providing Services to People with Disabilities on Tribal Lands

Members of federally recognized tribes have access to health services through the federal IHS that provides services to all eligible tribal members. Similarly, BIA is responsible for providing a variety of services that address the needs of people with disabilities (e.g., education and services to school-age children with disabilities). However, chronic underfunding of AI/AN programs by the Federal Government has severely lessened the ability of these federal agencies to meet the needs of the AI/AN population.

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[51] National Indian Justice Center, *op. cit.*, p. 18.

[52] *Ibid.*, p. 19.

Funding of Education Programs. Funding for special education programs for AI/AN children with disabilities is provided from a variety of sources from the U.S. Department of the Interior's BIA, U.S. Department of Education, and state education departments, depending on the type of school attended. Ninety percent of AI/AN children attend publicly funded schools and 10 percent attend BIA-funded schools, which are run by BIA, contractors, or tribes.

Responsibilities for providing special education and related services to AI/AN children ages 5 to 21 with disabilities reside with the school district in which they are enrolled. Since 90 percent of AI/AN children attend public schools, state and local governments are responsible for funding special education and related services for the vast majority of Indian children with disabilities. All BIA-funded schools that use IDEA allocations from the U.S. Department of Education, whether managed by BIA or tribes, are responsible for carrying out the IDEA requirements by providing special education and related services to eligible children with disabilities who may be among the remaining 10 percent of AI/AN children who attend BIA-funded schools. BIA reports that school administrators believe that funding for staff is still a factor that presents a challenge to fully meeting the requirements.[53]

Funding for Health Programs. IHS estimates that the funding it receives to care for eligible AI/AN people is only about 50 percent of actual need. On a per capita basis, IHS funding has declined by nearly 20 percent since 1987.[54] Total U.S. per capita spending for health care was $3,619 in 1998, compared with IHS funding of $1,186 per capita for American Indians who live on or near reservations and use IHS facilities. Total estimated per capita expenditures, paid through all sources of financing including out-of-pocket costs, for the American Indian population were about 58 percent of average U.S. per capita expenditures. For people who reside in Indian Country, however, it is likely that IHS-funded health services constitute the primary or only source of health care available. IHS reports that authorization for referrals to contract health

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[53] Office of Special Education Programs, Bureau of Indian Affairs Monitoring Report, U.S. Department of Education, Office of Special Education and Rehabilitation Services, April 20, 2000.

[54] Cox D and Langwell K, *Sources of Financing and the Level of Health Spending for Native Americans,* The Henry J. Kaiser Foundation, Washington, DC, October 1999.

services (i.e., services purchased outside the IHS because the needed services are not available directly from IHS) is currently limited to "emergent, saving of life and limb" due to limited funding.[55]

IHS direct service or tribally managed health programs may augment financial resources through Medicaid, Medicare, or State Children's Health Insurance Program reimbursement for services provided to patients who are enrolled in these programs. However, there are many barriers to enrollment in these programs and not all IHS or tribally managed health programs have the information system capabilities or third-party reimbursement experience to effectively obtain the reimbursements that they may be eligible to receive.

While health care is only one component of the services and support needed by people with disabilities living in Indian Country, the relative poor health status and the underfunding of the IHS reflects the general lack of financial resources directed by the Federal Government to meet health, education, vocational rehabilitation, independent living, and other service needs of all people living in Indian Country. People who have disabilities and need appropriate services to permit them to participate fully in society face grave barriers to obtaining these services and support in an environment where the available resources are vastly inadequate to meet basic needs of all tribal members.

Funding for Vocational Rehabilitation, Independent Living, and Assistive Technology Services. Federal funding for VR and independent living services is stipulated in the provisions of the Rehabilitation Act of 1973 as amended. Title I, Part C, Section 121 of the Rehabilitation Act establishes competitive grants for the provision of VR services to American Indians with disabilities. Indian tribes located on federal and state reservations are eligible to compete and receive grants under the American Indian Vocational Rehabilitation Services (AIVRS) program. Programs approved under Section 121 may be funded for a period of five years and must provide services that are comparable to those provided by state VR programs. The federal share of costs is equal to 90 percent of the costs of VR services; the remaining 10 percent, or the nonfederal

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[55] Indian Health Service, *Indian Health Care Services and Eligibility Information*, Rockville, MD (42 CFR 136.23).

share (which may be waived), may be rendered in cash or in kind. The 1998 amendments to the Rehabilitation Act set a reserve for programs funded through Section 121 at an amount greater than 1 percent and no more than 1.5 percent of federal appropriations for state VR grants. Currently, among the more than 560 federally recognized tribes, a limited number of 121 grants have been made available. Only 69 programs are in operation and among this small number, two receive no federal funds for their programs, but the tribes still work to meet needs of people with disabilities. The tribes funding their own programs are Sycuan (which is a consortia) in California and the Eastern Band of Cherokee in Cherokee, North Carolina.[56]

Independent living services and centers are funded through Title VII of the Rehabilitation Act. Title VII provides funds that states may use to provide independent living services, develop and maintain state independent living centers, and improve working relations between independent living programs, ILCs, state independent living councils, vocational rehabilitation, supported employment, and other federal and nonfederal programs established or supported through the Rehabilitation Act. Funds to provide independent living services are available through a grant mechanism. Tribal governments may apply to receive a Title VII grant; however, according to Lansing and Yazzie-King,[57] the success of tribal governments in obtaining funding for independent living services through this mechanism may be limited because "tribes must compete for these grants with the majority society, where greater knowledge of the independent living philosophy, the independent living movement, and federal requirements is already in place." Currently, only one ILC grant has provided a place for service on tribal land anywhere in the United States. Grants are administered through the U.S. Department of Education's RSA.

The Assistive Technology Act of 1998 provides funds through state assistive technology (AT) programs. There are 56 such federally funded programs, including one in every state,

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[56] Personal correspondence with Carleen Anderson, Region X: Rehabilitation Services, January 10, 2003.

[57] Lansing SP and Yazzie-King E, "Access to Independent Living and Assistive Technology for American Indians with Disabilities," in *Rehabilitation and American Indians with Disabilities: A Handbook for Administrators, Practitioners, and Researchers* (ed. by CA Marshall), Athens, GA: Elliot and Fitzpatrick, Inc., 2001, p. 76.

commonwealth, and territory of the United States.[58] Funds may be used, in part, to improve access to assistive technology, to increase consumer awareness of technology, and to develop alternative financing mechanisms, such as loan programs, for consumers to purchase assistive technology. Information on the extent to which these state programs meet the AT needs of American Indians with disabilities is unknown.

IHS provides access to only a relatively narrow set of AT devices (e.g., hearing aids, eyeglasses). Funding for assistive technology necessary for independent living must generally be obtained from various other sources. Assistive technology may be covered under Medicare, if the required services fall within the Centers for Medicare and Medicaid (CMS) definition of "durable medical equipment" or by Medicaid if services are deemed to be "medically necessary" and are covered under the different states' Medicaid plans or their waiver programs. An eligible child with a disability may have access to assistive technology (e.g., computer equipment, listening devices, and communication equipment) to meet needs identified by the IEP team to provide a free appropriate public education under the IDEA educational activities and support his/her opportunities for educational attainment through IDEA. State VR agencies and specifically the AIVRS programs may provide technological equipment including sensory and telecommunications devices; however, data from an evaluation of the AIVRS[59] suggests that the rehabilitation technology services available through these programs may be limited.[60] The effectiveness of these programs in assisting American Indians with disabilities to access assistive devices is not known but, based on lack of access to electricity, telephones, and cable, for

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[58] "RESNA Technical Assistance Project: AT Connections—State Assistive Technology (AT) Programs." Retrieved from www.resna.org/taproject/at/connections.html on March 18, 2003.

[59] Hopstock P, Baker C, Kelley J, and Stephenson T, "Evaluation of the American Indian Vocational Rehabilitation Services Program," Arlington, VA, Development Associates, June 30, 2002.

[60] Of the 54 AIVRS programs included in this evaluation, only seven indicated that they provided rehabilitation technology services to "some" or "most" of their consumers.

example, in remote/rural areas, it is widely believed that American Indians residing in Indian Country face significant barriers to accessing assistive technology.[61]

Limited Tribal Resources to Meet the Needs of People with Disabilities on Tribal lands

American Indians and Alaska Natives are among the most impoverished population groups in the United States. This is particularly the case for American Indians and Alaska Natives who live in Indian Country. Most tribal lands have small populations, with high levels of poverty and unemployment. In 1990, for instance, the second largest Indian reservation had a population of less than 12,000 and only 18 reservations had populations of over 5,000.[62] The limited population size seldom is sufficient to generate revenues for tribes that would enable them to directly fund any significant level of services to meet the needs of people with disabilities. Services are generally dependent upon a tribe's ability to develop programs through federal or state funding.

Diversity Among AI/AN Populations

There are over 560 separate federally recognized tribes and each has its own culture, history, health beliefs, and practices. There is also a diversity of languages among the AI/AN population; linguists recognize at least 62 language families among those spoken by American Indians.[63] Community attitudes and cultural beliefs about the causes of disabilities and perceptions differ substantially among tribes, with consequent differences in beliefs about appropriate responses and support that should be offered to people with disabilities.[64] As a result, designing and implementing culturally competent and culturally appropriate outreach programs and training disability services professionals to offer culturally competent services is not a simple task. There is not a generic approach that can be adopted and used across all tribal lands to address the needs

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[61] National Council on Disability, "Federal Policy Barriers to Assistive Technology," May 31, 2000.

[62] Snipp C, "Selected Demographic Characteristics of Indians," in *American Indian Health: Innovations in Health Care, Promotion, and Policy* (ed. by Rhoades E), The Johns Hopkins University Press, Baltimore, MD, 2000.

[63] Demalle R and Rhoades E, "The Aboriginal People of America," in *American Indian Health: Innovations in Health Care, Promotion, and Policy* (ed. by Rhoades E), The Johns Hopkins University Press, Baltimore, MD, 2000.

[64] National Indian Justice Center, *op cit.*, p. 14.

of people with disabilities. Programs must be tailored to the specific tribal population through significant input from tribal members. The Tribal Disability Actualization Process illustrates the tailoring of a one-to-one approach that is important when addressing disability policy and services issues with individual tribes. It involves bringing together a wide range of concerned tribal members, using a "self-directed" approach for tribes to develop disability legislation that respects tribal culture and sovereignty.[65] While the model developed by the Tribal Disability Actualization Process is a uniform one, it requires extensive work with individual tribes and community members to produce change in attitudes and effect change in policy. This process is described in more detail below. With over 500 tribes in the United States, implementation of this process across all tribes would require significant resources and time to accomplish substantial change on behalf of people with disabilities in Indian Country.

Assessing the Effectiveness of Strategies for Reducing Barriers to Provision of and Access to Appropriate Services

Although strategies to advance the independent living and self-determination realities of American Indians with disabilities have been initiated, the review of the literature indicates that the effectiveness of most efforts has not been empirically tested. The few studies that report an evaluation component are methodologically weak; small sample sizes and the use of subgroups that are not representative of Indian Country as a whole are among the factors that limit the ability to generalize findings from these studies to the larger population of American Indians and Alaska Natives with disabilities. Evidence on the extent to which initiatives have succeeded in removing barriers to education, health, vocational rehabilitation, and independent living among American Indians residing in Indian Country is primarily anecdotal, with limited information on trends or analyses of patterns across the data that might suggest similarity across findings.

Tribal Disability Actualization Process

Project staff at the University of Montana Rural Institute on Disability AIDTAC designed and evaluated a model to assist tribes in developing disability policy that reflects the tribe's culture

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[65] Fowler L, Dwyer K, Brueckmann S, Seekins T, Clay J, and Locust C, *American Indian Approaches to Disability Policy: Establishing Legal Protections for Tribal Members with Disabilities: Five Case Studies*, American Indian Disability Legislation Project, University of Montana, December 1996.

and values. This model is composed of four primary steps that are designed to increase tribal members' awareness of unmet independent living needs and enhance their understanding of the adequacy or appropriateness of existing tribal disability policies. In the first step of this process, a tribal member willing to advocate and assist in educating the community on disability issues is identified. In the second step, the authorization of the tribal government and support for the actualization process is obtained; typically, this is done through an educational presentation to tribal leaders. Step three consists of focus groups or "talking circles" in which tribal members (as well as invited state and local disability providers) discuss beliefs concerning disability, unmet needs, sovereignty issues, and approaches for establishing disability policy. In the final step in the process, focus group members present to their tribal governments a set of approaches for meeting the needs of people with disabilities through tribal legislation.

A qualitative evaluation of the impact of the Tribal Disability Actualization Process indicates that tribes that participated in this process have in fact engaged in a variety of activities that have resulted in an increased awareness of disability issues within their communities and address barriers to independence within the reservation. Among the outcomes attributed to the Tribal Disability Actualization model are the following: the Oglala Lakota Sioux Tribes in the Pine Ridge Reservation in South Dakota adopted ADA in 1994; in addition to making enhancements to ensure the accessibility of public buildings, tribes located in the Flathead Reservation of Montana adopted a resolution that conformed to the spirit of ADA and made modifications to policies to address hiring and training of people with disabilities; and the Navajo Reservation in the Northeast Arizona and Colorado Plateau initiated activities to arrange for personal assistance training for tribal members.[66]

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[66] Dwyer K, Fowler L, Seekins T, Locust C, and Clay J, "Community Development by American Indian Tribes: Five Case Studies of Establishing Policy for Tribal Members with Disabilities," *Journal of the Community Development Society*, 2000; 31(2):196–214.

Education

A number of strategies have been developed and implemented to increase the availability and effective use of special education and related services for AI/AN children with disabilities.[67] Several IDEA grants have been awarded to train special education teachers to work with AI/AN students. These include the Reaching American Indian Special/Elementary Educators (RAISE) project at Northern Arizona University and two relevant projects at Pennsylvania State University. The RAISE project provides opportunities for students to work directly with Navajo children in local communities and schools and offers experience with culture, language, and traditions. The Pennsylvania State University program provides training in special education and educational administration to AI/AN students and offers them opportunities to conduct research on improving education of AI/AN students with disabilities. Graduates of the program work in special education in AI/AN communities for two years for each year of funding they receive. In addition, the American Indian Higher Education Consortium reports that 34 tribal colleges operate in the United States. BIA reports that 27 tribal colleges receive BIA funding. Some tribal colleges receive grants to train special education personnel at all levels.

Programs are also available to provide education, support, and assistance to parents of AI/AN children with disabilities regarding rights and effective strategies to obtain services for their children. Currently, 106 Parent Training and Information Centers and Community Parent Resource Centers, funded by the U.S. Department of Education, are located throughout the United States. Technical assistance to the centers is provided by the Technical Assistance Alliance for Parent Centers. These centers provide training and information to parents of infants, toddlers, and school-aged children and young adults with disabilities, as well as the professionals who work with families. The assistance provided to parents helps them participate more effectively with school personnel and other professionals to meet the educational needs of children and youth with disabilities.[68] At least two of these centers specialize in assisting AI/AN

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[67] Faircloth S and Tippeconic J, "Issues in the Education of American Indian and Alaska Native Students with Disabilities," ERIC Digest, EDO-RC-00-3 (December 2000).

[68] Technical Assistance Alliance for Parent Centers, "Parent Training and Information Centers and Community Parent Resource Centers." Retrieved from www.taalliance.org/PTIs.htm on March 20, 2003.

families who have a child with a disability. The National Native American Families Together Parent Center (NNAFT), located in Moscow, Idaho, is directed and staffed by members of tribal communities. NNAFT provides information on the educational rights of children with special needs; communicating with school and medical personnel and other professionals; how to participate in developing and monitoring a child's educational plan; and disability-specific data on sensory, mental, emotional, or specific learning disabilities. The centers recruit and train community members to provide support and assistance to families of AI/AN children with disabilities.[69] The Native American Family Empowerment Center, located in Lac du Flambeau, Wisconsin, is a program of the Great Lakes Intertribal Council. This program seeks to ensure access to services for tribal families with children who have a disability, and other impairments as determined under IDEA. This program works to empower AI/AN families with knowledge to work with schools and state and local health and human services agencies.[70] These are two examples of programs with a special emphasis on AI/AN populations. However, it is important to point out that all of the federally funded parent centers across the country are charged to serve all families whose children have disabilities, including families in ethnically diverse populations.[71]

With regard to testing methods, Faircloth and Tippeconnic (2000) cite examples of school districts that have developed culturally and linguistically appropriate testing methods to distinguish AI/AN children with learning disabilities from those with cultural/linguistic barriers to learning to ensure that referrals for special education and related services are appropriate.

Although a variety of approaches have been designed and implemented to improve services to AI/AN children with disabilities, little data exists providing evidence of the impact of these

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[69] National Native American Families Together Parent Center, "National Native American Families Together Parent Center." Retrieved from www.nativefamilynetwork.com on March 20, 2003.

[70] Great Lakes Intertribal Council, "Native American Family Empowerment Center." Retrieved from http://glitc.bfm.org/programs/default.php.

[71] Jordan, Dixie, PACER Center, Inc., Minneapolis. Telephone interview by Martina Whelshula. March 20, 2003.

strategies on educational outcomes. In addition, since most educational services for AI/AN children with disabilities are provided through state programs (rather than on reservations through BIA-funded and tribally managed programs), the major barriers to appropriate educational services are similar for both AI/AN and non-AI/AN children with disabilities. However, cultural and language differences may create additional barriers for the effectiveness of mainstream services that are provided to AI/AN children.

Vocational Rehabilitation

Available evidence suggests that American Indians with disabilities who complete a program of vocational rehabilitation are likely to experience employment outcomes superior to American Indians who are not rehabilitated. A study that analyzed the employment status of 21 American Indians who participated in VR programs and 40 American Indians who participated in job training programs found that 85 percent of those who completed their VR program were employed following rehabilitation, compared with only 25 percent employment among American Indians, living on and off reservations, who were not rehabilitated. Similarly, 63 percent of American Indians who successfully completed a job training program or were "positively terminated"—meaning they were employed 13 months following the job training program—were employed, compared with only 8 percent employment among the population with training.[72]

The 64 projects that were supported through the AIVRS program in 2001 served approximately 4,500 persons.[73] Estimates suggest that of the consumers served by these AIVRS projects, over 28 percent had a substance abuse problem, 22 percent had an orthopedic disability, 17 percent had a mental or emotional disability, and 15 percent had a learning disability. Interestingly, in interviews with project staff conducted as part of an evaluation of the AIVRS program,

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[72] Gahungu A and Sherman JM, *An Examination of the Relationship Between Consumer Satisfaction and Employment Outcomes for Rehabilitated and Non-Rehabilitated American Indians*, American Indian Rehabilitation Research and Training Center, July 18, 2000.

[73] U.S. Department of Education, American Indian Vocational Rehabilitation Services Program Performance Report, 2001. Available at www.ed.gov/pubs/annualreport2001/333.html.

respondents indicated that American Indians/Alaska Natives with physical disabilities were most likely to be in need of but not receive AIVRS services.[74]

Although estimates were not independently validated, data reported to RSA by tribal VR agencies indicates that nearly 65 percent of American Indians who exited the AIVRS program in 2001 achieved an employment outcome.[75] In their evaluation of the AIVRS program, which was conducted under contract to RSA, Hopstock et al. noted that in fiscal years 1998 and 1999, only 53 percent of AI/AN consumers who exited state VR programs achieved successful employment outcomes.[76] During fiscal year 2000, 963 American Indians with disabilities were successfully rehabilitated under AIVRS programs. In addition to the successful rehabilitation, tribal VR programs served 4,178 AI/AN consumers. Thirteen tribes or consortia applied but were not funded in fiscal year 2000 for AIVRS programs. In the 2001 fiscal year, insufficient funds prevented 9 out of 14 tribes or consortia from being funded for AIVRS programs. With the potential to achieve positive results from AIVRS programs, reauthorization with an increase in funding is desperately needed.[77]

Vocational Rehabilitation: Native American Technician Program

The Native American Technician (NAT) program was established by the Florida State Vocational Rehabilitation Agency as a pilot rehabilitation program. The NAT program is

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[74] Hopstock et al., "Evaluation of the American Indian Vocational Rehabilitation Services Program," 2002.

[75] U.S. Department of Education, American Indian Vocational Rehabilitation Services Program Performance Report, 2001. Available at www.ed.gov/pubs/annualreport2001/333.html.

[76] Hopstock et al., "Evaluation of the American Indian Vocational Rehabilitation Services Program," 2002.

[77] The Consortia of Administrators for Native American Rehabilitation (CANAR) Legislative Committee developed a set of 11 resolutions for consideration by those who are responsible for reauthorization of the Rehabilitation Act of 1973, as amended. The resolutions were designed to promote the continuing growth of culturally responsive rehabilitation services for American Indians and Alaska Natives with disabilities. The resolutions were edited and finalized with input from CANAR members at the CANAR Annual Conference in Seattle, Washington, on December 11, 2001, and named "The CANAR 11." Retrieved from http://www.nau.edu/ihd/CANAR/legislation.html on January 10, 2003.

premised on the belief that because tribal members are most familiar with their American Indian values and culture, they are also best suited to conduct outreach in their respective communities. Through contractual agreements, the state arranged for Indian members of the community to assist non-Indian counselors in providing VR services to the Indian community. Among their responsibilities, NAT assisted the agency in case management and identified members of their community who were in need of but had not received VR services. Preliminary evidence suggested that the NAT program succeeded in increasing participation of American Indians in the state VR system.[78] However, the program lost funding sometime after 1996. In its place, a pilot program called the Native American Outreach Program was begun in Gainesville, Florida. Outreach counselors from the program attend powwows and tribal gatherings, where they inform American Indians with disabilities of available government programs and funding. Referrals and applications are provided as needed. Further follow-up will be needed to assess the outcomes of this program.

Vocational Rehabilitation: Self-Employment Options

The Jemez/Zia Vocational Rehabilitation Center in New Mexico and the Tanana Chiefs Conference Vocational Rehabilitation Program in Fairbanks, Alaska, are among the programs that are assisting American Indians with disabilities to achieve independence through self-employment. In addition to receiving training in budgeting and marketing, skills that are necessary to operate a small business, the Jemez/Zia program employs tribal people with disabilities to train clients in one of several crafts, such as pottery making or silversmithing. Among the successful outcomes that the Tanana Chiefs VR program seeks is for clients to enter into competitive employment, become self-employed, or engage in subsistence hunting, fishing, and trapping. Subsistence hunting and fishing are respected as culturally appropriate and as an exercise of a person's right to self-determination. Both the Jemez/Zia and the Tanana Chiefs programs assist clients in purchasing or obtaining supplies and equipment to operate the clients' businesses. Emerging patterns across anecdotal evidence indicate that these programs are

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[78] Locust C and Lang J, "Walking in Two Worlds: Native Americans and the VR System," *American Rehabilitation*, Summer 1996: 2–11.

succeeding in their goal of assisting people with disabilities to move toward economic self-sufficiency; however, empirical evidence of these impacts is unavailable.[79]

Independent Living and Transportation in Indian Country

Recognizing that a weak transportation infrastructure may limit economic opportunities and pose a substantial barrier to accessing essential health and social services, several tribes have developed transportation systems that may be replicated. For instance, with funding from RSA, the tribally controlled Salish Kootenai College (SKC) on the Flathead Reservation of Montana developed a point-to-point transportation system for residents of the reservation with disabilities. The SKC transportation program purchased wheelchair-accessible vans and coordinated access to employment and rehabilitation services as needed by both tribal and nontribal members of the community. An early (six-month) evaluation of this program indicated that ridership was below initial projections. Eligibility limitations and difficulties in advertising availability of services in rural communities were thought to account for this initial low rate of use.[80] Current information on the status of this program was not available for this NCD report.

Several tribes have also used funding obtained from a combination of federal and state sources (e.g., the Federal Transit Administration, the HHS' Administration on Aging, Medicaid) to develop transportation systems that are accessible to people with disabilities. These systems were designed to link tribal members to employment centers and health and human services programs. Among the tribes with such transportation systems, the Chickasaw Nation Transportation System in Oklahoma, the Navajo Transit System in Arizona, and the Shoshone and Arapaho Nation Transit Association in Wyoming operate paratransit vans or vehicles that are fully accessible or

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[79] CANAR, "Business Incubator Promotes Self-Employment," *CANAR: Newsletter for American Indian Vocational Rehabilitation Programs*, 2001; 3(2):1-2. CANAR, "Self-Employment and Subsistence Hunting and Fishing in Alaska," *Newsletter for American Indian Vocational Rehabilitation Programs*, 2001; 3(2):3–4.

[80] Hermanson M, Landstrom B, and Domitrovitch J, "Developing a Transportation System for Individuals with Disabilities on a Rural Indian Reservation," *American Rehabilitation*, Autumn 1994: 28–31.

ADA compliant.[81] Although it may be reasonable to assume that these transportation systems enhanced the independent living opportunities of people with disabilities living in Indian Country, empirical evidence is not available in the literature.

Independent Living and Training Models for Sensitivity

Staff of AIRRTC developed and pilot-tested an independent living training workshop to provide technical assistance to service providers and policymakers on the provision of outreach services culturally appropriate to AI/AN clients with severe disabilities. The purpose of this training module was three-fold: "(1) identify differences among American Indian cultures…(2) create outreach independent living services for American Indians with severe or significant disabilities on and off Indian lands, and (3) identify strategies related to the independent living needs of American Indians."[82] The training module assists participants in developing "Blue Prints for Action Plans"—strategies for providing outreach to American Indians with disabilities—and identifying resources to implement the plans. Reports of results connected with outreach training at one month, three months, and six months suggested that the 16 program participants were able to identify and/or had taken action toward implementing outreach strategies to assist AI/AN clients with disabilities to achieve their independent living objectives.

Staff of the Northern Arizona University also developed a program to train American Indian community representatives to understand and address the independent living needs of elderly American Indians with visual impairments. Representatives from tribal health departments, senior citizen programs, and other service programs were invited to participate in a five-day workshop in which hands-on training on topics such as the techniques for mobility and daily living, assistive devices, and cultural and rural issues were provided. The 38 trainees were required to practice newly acquired skills with visually impaired volunteers. Following the workshop, an in-service training with tribal members was conducted to address the specific needs

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[81] Shawn K, "American Indian Transportation: Issues and Successful Models," *Technical Assistance Brief* #14, RTAO National Transit Resource Center. Retrieved from www.ctaa.org/ntrc/rtap/pubs/ta/am_ind.html on May 31, 2002.

[82] Sanderson PL and Clay JA, *Strategies on Successful Independent Living Services for American Indians with Disabilities: A Research Dissemination Final Report,* American Indian Rehabilitation Research and Training Center, Northern Arizona University.

of the reservations. Evaluation of the workshop was conducted using a pre- and post-test design. The improvement in test scores suggested that the workshop objectives had been met. Study investigators reported that the community representatives who were trained under this one-year program served a total of 211 American Indians with visual impairments.[83]

Independent Living and Personal Assistance Services

Recognizing the need for culturally sensitive personal care services, the Blackfeet tribal council adopted and guaranteed start-up funds for the Blackfeet Personal Care Assistance (PCA) program. The program hires, trains, and arranges for attendants to provide services to tribal members. The program also provides case management services for elderly tribal members with dementia or Alzheimer's disease and has worked to bring independent living apartments to the local community. The Blackfeet PCA program is believed to be among the largest of the personal assistance providers operating in the State of Montana. Most clients are Medicaid-eligible, and funding for program services is obtained largely through Medicaid. Anecdotal evidence suggests that tribal members favorably received the Blackfeet PCA program and that the program has contributed to the local economy through the hiring and training of personal assistants.[84]

A Single Independent Living Center in Indian Country

ASSIST! to Independence is a Native American–operated nonprofit organization that has been very effective in reducing barriers to the provision of, and access to, appropriate services for those tribal members living on reservations. ASSIST! is located on the western edge of the Navajo Reservation in Tuba City, Arizona, and provides services to individuals with disabilities, or chronic health conditions, residing on or near the Navajo, Hopi, and Southern Paiute Reservations. At present, it is the only ILC located in Indian Country.

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[83] Martin WE, White K, Saravanabhavan RC, and Carlise K, "Training Programs for Working with Older American Indians Who Are Visually Impaired," *American Rehabilitation,* Summer 1993: 2–6.

[84] Spas D, "People with Disabilities, Employees, a Local Rural Economy: Everybody Wins with the Blackfeet PCA Program," *Common Threads*, Summer 1999. Available at http://ruralinstitute.umt.edu/rtcrural/indian/AmICT.htm.

ASSIST! provides culturally relevant services to cross-disability American Indian consumers and its programs emphasize quality of life and community access through the maximization of independence and the improvement of functional skills. Community members with disabilities created ASSIST! to respond to the need for a more flexible service delivery system, where all services reflect the following independent living principles: (1) it is consumer controlled at the operating policy level with a board of directors that consists of a majority of people with disabilities; (2) the majority of administrative and staff-level personnel are represented by people with disabilities; (3) there is an emphasis on cross-disability consumer services; (4) there is an emphasis on peer role modeling and consumer-controlled service objectives; and (5) the four core services of advocacy, peer mentoring, independent living skills training, information and referral are provided. In addition, ASSIST! has provided services such as home modifications, transportation, attendant care, assessment and evaluation, and AT demonstration/loan.[85]

In 2002, ASSIST! was one of four winners of The Association of Programs for Rural Independent Living's competition for The Best Center for Independent Living Practices in Rural Independent Living to Emerging Disability Populations.[86] Also, in 2002, ASSIST! was recognized by the National Council on Independent Living as a Best Practice for Assistive Technology Projects.[87]

The main factors contributing to the ability of ASSIST! to successfully reduce barriers to the provision of and access to appropriate services for tribal members living on reservations are (1) dynamic and fluid services allowing for a quick response to needs; (2) understanding, respecting, and immersing in the culture being served; (3) aggressive outreach promoting "wellness" services; (4) extensive networking and collaboration activities; (5) developing relationships with nontraditional disability specialists (senior centers, public health nurses, community health

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[85] "Best CIL Practices in Rural Independent Living." Retrieved from http://www.rtcfpil.org/best_cil_practices_in_rural.htm on March 18, 2003.

[86] Diana Spas, Electronic Mail, Subject: "The winners of APRIL's Best Practices Competition!" ASSIST! to Independence, August 8, 2002.

[87] Maureen Ryan, Electronic Mail, Subject: "Best Practice AT Projects," ASSIST! to Independence, July 31, 2002.

representatives, etc.); and (6) maintaining a visible presence in the community (senior functions, health fairs, etc.).[88]

Statistical data, maintained by ASSIST!, exemplifies the positive impact that this organization has had on tribal members with disabilities living on reservations. Between October 1, 2001, and September 30, 2002, ASSIST! opened a case file and conducted ongoing case management for 1,098 individuals with disabilities, of all ages; processed 415 phone and e-mail requests; assisted 784 people who visited the center (721 of whom were American Indian); and conducted 143 off-site visits.[89]

Of the many individuals served by ASSIST! in 2002, roughly 85 percent were referrals received from collaborative efforts developed with community health representatives and public health nurses. The remaining 15 percent were individuals who investigated independent living services on their own. Approximately 70 percent of the ASSIST! budget is devoted to direct consumer services.[90]

Limitations to Understanding Issues of People with Disabilities Living in Indian Country

It is difficult to ascertain the extent to which many programs or initiatives actually impact outcomes since many of the studies or programs identified in the literature, particularly literature on effective strategies for reducing barriers to access, do not include a formal evaluation component. In some cases, failure to evaluate program effectiveness was attributed to lack of funds. In those cases where a formal evaluation appears to have been conducted, small sample sizes, failure to account for confounding factors, and the lack of a control group for comparison make it difficult to determine the actual effect of these initiatives or whether these model programs may be successfully replicated in other tribes or settings.

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[88] "Best CIL Practices in Rural Independent Living." Retrieved from http://www.rtcfpil.org/best_cil_practices_in_rural.htm on March 18, 2003.

[89] Pifer, Beth. Assist! to Independence. Telephone interview. March 20, 2003.

[90] "Best CIL Practices in Rural Independent Living." Retrieved from http://www.rtcfpil.org/best_cil_practices_in_rural.htm on March 18, 2003.

Much of what is currently known about people with disabilities living in Indian Country—from estimates of the size of the population to information on the impact of barriers to successful education, health, vocational rehabilitation, and independent living outcomes—has been based primarily on anecdotes, individual perceptions, and/or studies with limited statistical validity. The ability to use the information gathered from these studies to identify the unmet needs of American Indians and Alaska Natives with disabilities who reside in Indian Country may be limited by flaws in the methodological or research design and the failure of some studies to understand the characteristics of the AI/AN population.

For instance, data on the size of the AI population with disabilities and the nature or types of disabilities that they experience is among the most basic information for understanding their unmet needs. Yet, the reliability or precision of the estimates that are presently available are affected by discrepancies in the classification of people as American Indians and Alaska Natives, small sample sizes, inconsistent definitions of terms for types of disabilities, and use of nonrepresentative samples to derive these figures. The understanding of trends in the growth of the AI/AN population is significantly affected by changes in the reporting of race and ethnicity that occurred between the 1990 and 2000 censuses and specifically the change from single to multiple race groups. As previously discussed, depending upon whether individuals of multiple races are included, estimates of 10-year growth in the AI/AN population range between 26 percent and 110 percent. This wide variation makes large-scale program planning more challenging.

Information on the characteristics of the American Indian population with disabilities that are derived from national surveys and even those surveys that are commonly used to study disability-related issues (e.g., the National Health Interview Survey, the Medicare Current Beneficiary Survey, SIPP) are often not statistically reliable for analyses of certain populations of people from diverse cultures. The size of the AI/AN population is small relative to that of other groups and the number of American Indians and Alaska Natives with disabilities is an even smaller population segment. If oversampling techniques have not been applied, the margin of error associated with these estimates could be relatively large. This sampling issue is one of the

primary reasons why many studies do not analyze data separately for population segments of people from diverse cultures.

Service records, such as RSA data on VR closures or IHS hospital discharge data, have also been used to gain an understanding of the types of chronic and disabling conditions that are most prevalent among American Indians and Alaska Natives. Although analyses of the characteristics of American Indians and Alaska Natives with disabilities that are conducted with this data may not be affected by small sample sizes, they may have poor external validity. People who utilize these services may not be representative of the target population, and the ability to generalize findings from these studies to the larger AI/AN population may be limited.

Social and environmental factors, such as the high poverty rate and poor living conditions, may also make it more challenging for people studying the American Indian population. As noted by investigators in the Strong Heart Study, the recruitment of American Indians in studies may pose particular difficulty because "[d]ocumented historical events may also affect the spirit of cooperation in government-funded studies of the AI people...."[91] Practical considerations such as the lack of street addresses, telephones, and transportation also make it difficult for American Indians with disabilities who are living in Indian Country to participate in health and social services programs or in studies that assess and attempt to address their unmet independent living needs.

Tribal values are likely to affect the adequacy and comprehensiveness of many studies dealing with access to and services for people with disabilities in Indian Country as well as tribal members' willingness to participate in initiatives to reduce barriers. AI/AN culture, languages, traditions, and beliefs concerning health and disability are distinct across tribes. Studies that "combin[e] groups as separate as Seminole and Sioux into one category called 'Indian' seem little different than combining Polish Jews and Scottish Protestants into one category called

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[91] Stoddart ML, Jarvis B, Blake B, Fabsitz RR, Howard BV, Lee ET, and Welty TK, "Recruitment of American Indians in Epidemiologic Research: The Strong Heart Study," *American Indian and Alaska Native Mental Health Research, The Journal of the National Center*, 2000; 9(3):20–37.

'European'."[92] Regardless of the intended benefits, a program that fails to incorporate cultural beliefs will have difficulty in obtaining community support. Similarly, a study that is not culturally competent may obtain incomplete or inaccurate information. As one example, the word "disability" is often value-laden. Depending on tribal beliefs and values surrounding the term, American Indians who are asked to self-identify on the basis of disability may be reluctant or refuse to participate in programs that promote independent living objectives, vocational rehabilitation, or special education. Participatory action research methods, such as that used in the Tribal Disability Actualization model, which includes consumers in the design and implementation process, have been recommended as a means to ensure that research is culturally sensitive and findings are both accurate and relevant.[93]

Federal Responsibility to Address Gaps in Knowledge

This study begins to scratch the surface of understanding the issues faced by people with disabilities in tribal communities. Federal agencies with significant trust responsibilities to Indian tribes must become much more engaged with and committed to addressing the gaps in research, services, and protections related to this population. Specifically, the U.S. Departments of Education, Interior, Justice, and Health and Human Services have particular interest in better understanding people with disabilities in tribal communities. Although a substantial amount of literature addresses issues relevant to access to and use of services by people with disabilities in Indian Country, the issues discussed above may limit the usefulness of much of the research. This is of particular importance when research-based evidence is sought for planning and developing effective strategies to increase services to people with disabilities in Indian Country.

On the basis of available existing research and data, conclusions may be drawn as follows:

1. A significant number of American Indians and Alaska Natives in Indian Country have disabilities.

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[92] Ericksen EP, "Problems in Sampling the Native American and Alaska Native Population" in *Changing Numbers, Changing Needs: American Demography and Public Health.* National Research Council Committee on Population, National Academy Press, Washington, DC, 1996.

[93] Davis SM and Reid R, "Practicing Participatory Research in American Indian Communities," *American Journal of Clinical Nutrition,* 1999; 69(4 Supp):755S–759S.

2. Services and accommodations to assist people with disabilities in Indian Country are limited and availability of supports and services varies across Indian Country.

3. Limited legal protections, limited financial resources, and lack of awareness about the needs of and strategies for enhancing opportunities for people with disabilities are major barriers that must be overcome to increase availability of appropriate services in Indian Country.

4. Cultural awareness and competency are important aspects of any strategy to increase knowledge and awareness of the needs of people with disabilities and to design and implement effective programs to meet those needs.

5. The complex federal-state-tribal government relationships and the complicated maze of programs that fund and administer implementation of laws and programs serving people with disabilities pose communication and coordination barriers to improving the provision of services in Indian Country.

The potential for developing effective strategies to increase the availability and use of services to people with disabilities in Indian Country would be enhanced by additional data collection and research in several specific areas, including

- Collection of systematic data on the number of people with disabilities in Indian Country, by type of disability and geographic location
- Identification of the service needs of people with disabilities in Indian Country, by geographic area
- Comprehensive review and documentation of existing programs and current services available in Indian Country, by geographic area
- Estimation of the gap between need and available services, by geographic area
- Identification of promising practices, or what seems to be working effectively, based on outcomes, for education, health, vocational rehabilitation, and independent living

American Indians and Alaska Natives constitute a very diverse set of multiple cultures, traditions, and languages that make it difficult to generalize findings from research in a generic way. As a result, research designed to provide a foundation of knowledge for designing and implementing strategies to increase the availability of services to people with disabilities in Indian Country will require early involvement in planning and decisionmaking, as well as leadership and direction by AI/AN researchers and program managers. In addition, findings from future research will require adaptation and modification to be effective in different tribes.

Key Respondent Interviews

> *"The perspective I think we need to take is a national perspective, which is not just about our own tribe but about all native people."*
>
> *—LaDonna Fowler, Turtle Mountain Chippewa/Santee Sioux/Assiniboine*

The core research strategy in this project was an interview and focus group methodology that provided a free-flow process of information gathering. Open-ended qualitative interviews allowed a flow of feedback to inform and guide the research. The following techniques were used for deepening the inquiry into the issues affecting people with disabilities in Indian Country:

- Tribal and federal key respondent interviews
- Focus group interviews
- Informal talks with professionals and community advocates

Methods for analyzing and interpreting qualitative interviews vary widely. For this report, Technical Expert Panel (TEP) members expressed a desire for a participatory approach toward research. This method appears to be more congruent with AI/AN cultures. The analysis and interpretation of data through a participatory approach with the TEP assisted stakeholders in the construction of a common body of knowledge. The TEP and interviewees served as co-researchers in the project. As new information emerged from the interviews, there was an inquiry into the meaning of the information, what the information suggested, and why. This process generated new questions, thereby deepening the inquiry that served to test the explanations or confirm interpretations. Each phase of the process included gathering, interpreting, testing, and

revising information until a reasonable explanation was developed. Once the analysis was complete, stakeholders collaborated on findings, conclusions, and recommendations. In addition to summarizing the tribal and federal interviews, the following section also highlights promising practices and model approaches identified as examples of improving government-to-government relationships, as well as expanding services for people with disabilities living in Indian Country.

The discussions with key respondents from the 10 tribal communities occurred between September 9, 2002, and January 13, 2003. The 10 tribes were selected from a list of tribes recommended by the TEP. The TEP members were asked to nominate tribes that they believed to be actively engaged in developing programs, services, or tribal laws/ordinances that address the needs of people with disabilities in their communities. On the basis of this preliminary list, tribes were sorted to provide geographical representation across the United States and to reflect diversity in the size (small, medium, large) of the tribes. Finally, only tribes who agreed to participate in this project were interviewed. In alphabetical order, the 10 tribes interviewed were the Confederated Salish and Kootenai Tribes of the Flathead Reservation, Montana; Cook Inlet Tribe of Alaska; Hopi Nation of Arizona; Navajo Nation of Arizona, New Mexico, and Utah; Oglala Sioux Tribe of Pine Ridge, South Dakota; Oneida Nation of Wisconsin; Pueblo of the Zuni, New Mexico; St. Regis Mohawk of New York; Three Affiliated Tribes of North Dakota; and the Yakama Nation of Washington State.

Tribal Interviews

As stated earlier, each tribe addresses the unique circumstances of tribal members with disabilities in very different ways. The task was to identify those tribes across the country that demonstrated leadership in creating awareness, developing programs, adopting tribal laws, and meeting the needs of its tribal members and descendants with disabilities. Leaders and advocates in the Indian Country disability movement recommended 16 tribes for a nationwide inquiry about promising practices in leadership as described above. Of the 16 tribes recommended, 10 were randomly selected for follow-up interviews. Letters sent to the tribal leaders of each tribe introduced the research project and requested permission for representatives of their tribal programs to participate in the interview process. Interviews were then scheduled with appropriate program directors.

Discussion guides for interviews touched upon tribal government support through the development of disability laws, support services, major barriers, and promising practices for people with disabilities; access to health care; barriers to health care; children with disabilities who are treated differently; available employment services through the tribe; and what types of information or resources would be helpful to tribes. The tribal program representatives' interviews provided more than ample information, and wisdom was shared during the brief discussions.

Confederated Salish and Kootenai Tribes

In 1995, the Tribal Council of the Confederated Salish and Kootenai Tribes (CSKT) adopted a resolution in the same spirit as ADA.[94] Under the guidelines set forth by this resolution, the tribe modifies buildings or work environments according to the access needs of tribal members with disabilities. The CSKT have adopted a "one-stop shop" approach to providing services to tribal members with disabilities. At one location, tribal members can access not only VR services, but also, under a Temporary Assistance for Needy Families (TANF) grant, Medicaid, commodities, General Assistance, cash assistance, trust management, Individual Indian Money accounts, childcare, and senior care. Satellite offices in smaller towns help to increase the accessibility of services. By integrating services, the staff and management of these programs are able to make better use of resources, which improves service coordination and delivery of services to tribal members with disabilities.

The promising approach taken by the CSKT entailed networking and developing coordinated services through partnerships within agencies in the tribe as well as with agencies and organizations external to the tribe. The VR director for the CSKT also serves on the state rehabilitation council and the State Independent Living Board. In addition to strong partnerships developed with Salish Kootenai College, she attends conferences to keep abreast of the changes in and developments of programs, funding, grants, and service opportunities.

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[94] Templer, Arlene. Confederated Salish and Kootenai Tribes. Telephone interview by Martina Whelshula. September 10, 2002.

Cook Inlet Tribe

The Cook Inlet Tribal Council, located in Alaska, has a Section 121 Vocational Rehabilitation Program that serves the Cook Inlet Region.[95] The Cook Inlet Tribal Council faces different challenges than tribes in the lower 48 states, as their lands and jurisdiction are not necessarily "reservation based" but are based on village affiliation, with some Native and village land allotments. The program is in its third year of operation. Participants must have either a tribal or Native village affiliation. In many of the villages there is no economic base and unemployment may exceed 50 percent of the population. Lack of transportation is also an extreme barrier to employment.

Over 70 individuals with disabilities currently receive assistance through the Cook Inlet VR program. To help tribal members with disabilities overcome obstacles, each tribe provides different employment-related services, which range from career guidance and training to a consumer work center on the Internet. The VR program provides services as outlined in the Rehabilitation Act and is in the beginning stages of a school-to-work transition program. The Cook Inlet Tribe is also outlining VR procedures with the state to further collaborative efforts. People with disabilities benefit by the coordination of services offered through Cook Inlet, including assistance with the state's TANF and other resources.

Hopi Nation

The Hopi Nation's continuum of services for tribal members with disabilities extends from early infant and childhood intervention to adult VR services with their recent award of a Section 121 grant.[96] Grassroots parent advocacy has been at the heart of the Hopi Nation's service approach. In 1996, the tribes established the Office of Special Needs. Since the Office was formed, partnerships within the community and with national organizations have helped it to grow and become a community resource. These partnerships have allowed the Office of Special Needs to host training and education sessions on topics such as Social Security, fetal alcohol syndrome

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[95] Whitebear, Len. Cook Inlet Tribal Council. Telephone interview by Martina Whelshula. September 25, 2002.

[96] Talaswaima, Rhonda. Hopi Nation. Telephone interview by Wendy Thompson. September 13, 2002.

and fetal alcohol effect, parent mentoring, and caregiver training. These trainings provide the Hopi community, including families of children with disabilities, with an increased awareness about issues and resources for Hopi children with disabilities.

The Special Needs Activity Day held each year exemplifies the unique community approach that this program has taken. Since 1996, attendance at the event has grown from a core of interested parents to 600 participants last year. The theme is "Celebrate Diversity—Everyone is Unique." Support for the events, activities, and refreshments is provided in part by a grant from the Arizona Governor's Council on Developmental Disabilities. In addition, other Hopi community programs and outside agencies volunteer their time to make this event so successful. The Hopi Nation, by creating a central office to assist people with disabilities, has vastly improved the understanding of its community, the awareness of tribal programs, and the access, support network, and services for individuals with disabilities and their families.

Navajo Nation

The Navajo Nation tribal VR program was the first tribal VR program in the country, paving the way for other tribal VR programs in the nation. In the mid-70s, Navajo Nation leaders recognized a serious gap in VR services to tribal members with disabilities. This gap was due, in large part, to the fact that the Navajo Nation spans the corner of three states: Arizona, New Mexico, and Utah. Concern about this gap in services sparked negotiations between the Navajo Nation and surrounding states. Navajo leaders provided strong testimony during the reauthorization of the Rehabilitation Act during the mid-1970s. Because of the Navajo Nation's unique position in a tri-state area, Navajo leaders felt that their tribe needed to be funded directly rather than having funds funneled through each state office. This made the Navajo Nation the first tribe to receive the funds under the RSA grant, which provided greater access to vocational rehabilitation for tribal members with disabilities. Currently, this program is funded through a five-year grant from the U.S. Department of Education's RSA.[97]

Serving Navajo children are 32 schools located on and off the Navajo Reservation. It is estimated that 85 percent of the student population in these schools are Navajo children. The director for

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[97]Seanez, Paula. Navajo Nation. Telephone interview by Martina Whelshula. January 6, 2003.

Safe Schools and Healthy Students and former council member of NCD believes that schools need to focus more on career development for Navajos with disabilities.[98] Students are not typically encouraged to continue with any education beyond high school.

Support to provide individuals with the assistive technology they need has been obtained through a loan to the tribe from the Department of Vocational Rehabilitation. This unique service allows consumers to try out AT equipment on a loan basis to see what works for them. The Navajo Assistive Bank of Loanable Equipment Consortia is an organization composed of professionals from a variety of fields with the goal of assisting people with disabilities. The needs of individuals with disabilities are addressed in tribal regulations that were developed approximately 15 years ago by consumer advocates who gave testimony at an open tribal council meeting on topics such as special education, vocational rehabilitation, employment, and housing. These comments were then used as the basis for current tribal legislation.[99]

While the effectiveness of many of the Navajo Nation's programs and services for individuals with disabilities has been hampered by barriers caused by jurisdictional overlap, language, and geographic remoteness, the tribal government has worked to offset these barriers and uphold its responsibility to tribal members with disabilities through a unique financial trust fund for programs and service provision. About 10 years ago, a former president of the Navajo Nation oversaw the set-aside of monies obtained from renegotiation of land lease contracts for agencies that provide services to Navajos with disabilities, including border towns. Each year a committee that manages the trust fund reviews proposals from agencies and awards grants from the interest accrued by this trust fund. Grants have been awarded to provide for needs of tribal members with disabilities, which have ranged from creative employment options to improving rehabilitation services and decreasing agency caseload.

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[98] Yazzie-King, Ela. Navajo Nation. Telephone interview by Martina Whelshula. January 13, 2003.

[99] *Ibid.*

Oglala Sioux Tribe

The Oglala Sioux Tribe passed the Americans with Disabilities Act in 1991.[100] It is the only tribe thus far to undertake the step of adopting within its own tribal code the entire ADA, thanks in large part to the power of leadership within the tribal council, which included at that time a tribal member with a disability and member of the "Quad Squad," a grassroots advocacy group for people with disabilities. However, tribal interviews report that enforcement of the ADA provisions, particularly with regard to physical infrastructure and parking, is still a problem.

The Oglala Sioux Tribe's Quad Squad has become an active advocate for people with disabilities. The Quad Squad collaborates with state agencies to help consumers find support services. Although most support services are provided through the state, many people did not know how to obtain them. The Quad Squad helps increase the access that tribal members with disabilities have to resources, assistive technology, and employment by helping and advocating for them. As advocates for people with disabilities, the Quad Squad has worked for safe and accessible sidewalks, crossing lights, housing, transportation, and purchases of wheelchairs and other equipment.

Oneida Nation

Located in Wisconsin, the Oneida Nation has developed a strong employment-centered service program and has had success in finding work placements for many tribal members with disabilities. In 1995, the Job Training Program was developed because tribal members with disabilities were not receiving the kind of assistance they needed from state or other employment programs.[101] Program enrollment and dropout rates identified this service as one that needed to be addressed from a tribal perspective. The job center was designed as a one-stop service approach that provides mental health, childcare, and other related services in a seamless delivery. Developing employment opportunities through participation in a workforce diversification initiative has helped to reduce employment barriers for tribal members with disabilities. The tribe

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[100] White, Jo. Pine Ridge Oglala. Telephone interview by Martina Whelshula. September 9, 2002.

[101] West, Steven "Corky." Oneida Nation. Telephone interview by Martina Whelshula. September 26, 2002.

also supplements funding for its IHS health clinic to provide four doctors and a complete nursing staff.

The next goal that the program has set for itself is extending the reach of its services to include those tribal members who may be reluctant to identify themselves as people with disabilities or to ask for help.

Pueblo of the Zuni

The Pueblo of the Zuni, located in Northwest New Mexico, is the largest of 19 pueblos in New Mexico.[102] The population is approximately 11,000 people, of which about 96 percent are enrolled tribal members. The area is remote and isolated and covers about 1,000 square miles.

The tribe has a comprehensive array of services for tribal members with disabilities, which include supported and assisted living services and employment services. Supported living and assisted living services allow tribal members with disabilities to live more independently. Supported living provides one-on-one services on a 24-hour basis. Assisted living provides services for individuals with the ability to live more independently. Employment support, which includes supported employment, vocational rehabilitation, and day habilitation, provides tribal members with disabilities with increased opportunities for employment.

An extensive public transportation program supports people with disabilities as well as other members of the community. Last year the transportation program provided approximately 33,000 trips around the community. Transportation services are funded by multiple sources. The tribe has a Section 5311 grant that assists with administrative monies and capital and recently received approval to provide transportation under the Medicaid program. The transportation program also serves as a mechanism to employ people with disabilities.

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[102] Alflen, Larry. Pueblo of the Zuni. Telephone interview by Martina Whelshula. September 24, 2002.

St. Regis Mohawk Tribe

The St. Regis Mohawk tribal government has been active at the local, regional, and national levels in promoting tribal resolutions to address disability issues.[103] The tribe is in the process of implementing tribal codes that pertain to disabilities.

The St. Regis Mohawk Tribe collaborates with the county, state, and federal governments to offer a wide array of services to people with disabilities, ranging from family support programs to vocational rehabilitation. The tribes have a family support program that provides transportation to appointments and grocery shopping, which gives tribal members with disabilities increased mobility. A respite service for parents of children with disabilities provides support to families who have children with disabilities living in the family home. An adult recreation program and an inclusive afterschool recreation program are also available, so that tribal members with disabilities can be active community members.

Members of the staff for the tribal VR program have an excellent working relationship with the state VR program staff. This increases the level of effectiveness for services that can be provided to participants.

Three Affiliated Tribes

The Three Affiliated Tribes report that the tribal government has adopted requirements to protect and serve people with disabilities in their communities. The tribe's legal services department is called upon to help tribal members with disabilities resolve any complaints or appeals. Services and support for people with disabilities are coordinated through the tribes' Social Service Program. Networking and personal attention have been keys to the success of the Three Affiliated Tribes' Social Services Program.[104] The Social Services staff is knowledgeable about the services available through both the tribe and other agencies, thus making them better prepared to help tribal members with disabilities get their needs met.

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[103] LaFrance, Rita. St. Regis Mohawk Nation. Telephone interview by JoAnn Kauffman. September 13, 2002.

[104] Finley, Darlene. Three Affiliated Tribes. Telephone interview by Martina Whelshula. September 9, 2002.

The Three Affiliated Tribes provide General Assistance and grants to families, including people with disabilities. The Social Services Program will also research other services for which tribal members with disabilities may qualify and provide advocacy for them at tribal, state, and federal levels. The Program has found that assigning one person to follow the client through the entire application process increases the effectiveness of obtaining services. Working in collaboration with county, state, and federal agencies, the Three Affiliated Tribes can better serve clients.

Yakama Nation

Services for individuals with disabilities living on the Yakama Reservation are provided through the tribal VR program, the IHS clinic system, the Community Health Representative program, the Veterans' Affairs program, and the Home Health program.[105] In the past, the welfare-to-work program was used to provide transportation services; however, funding is no longer available. There are ongoing attempts through memoranda to educate the tribal council about the needs of tribal members with disabilities, such as providing curb access to public tribal buildings. Diabetes and alcoholism are the disabilities with the greatest impact on the community and where services are currently focused.

The promising approach taken by the Yakama Nation involved education, outreach, and program development. To accomplish this goal, the Yakama Nation hosted a 2002 Regional Disabilities Conference. Area programs had the opportunity to come together, share experiences, and learn from each other. The VR program director believes that ongoing workshop and program opportunities for awareness and collaboration and developing coordinated services between state and tribal programs are essential to strengthening the local services and resources available to tribal members with disabilities.

Key Elements of Promising Practices

Leaders and advocates in the Indian Country disability movement recommended tribes that exemplified successful practices that enhanced program and/or service results for people with disabilities. Of the 16 tribes recommended, 10 were selected for follow-up interviews.

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[105] Pratt, Linda. Yakama Nation. Telephone interview by Martina Whelshula. September 23, 2002.

Throughout the interviews with leaders of tribal programs and services, certain themes emerged across the different tribes. The themes of leadership and program qualities appeared to be key elements of success. This rich information can be shared with all tribal communities desiring to improve their tribal community environment for members with disabilities. The following section summarizes key elements for these promising practices identified in tribal communities.

Leadership Characteristics

A program leader who embodies the qualities and characteristics of passion, perseverance, vision, commitment, change agents, consistency, and connection and who is seen as an agent of hope can influence greatly the success of a program. Appendix F provides a more detailed description of common qualities and characteristics.

Responsiveness to the Needs of the Consumer

Successful programs require staff to know their consumers well. This requires moving beyond the initial identification of consumer needs to the development of personal relationships with consumers in order to truly understand the realities experienced by tribal members with disabilities. These programs tailor their services to the unique needs presented in each tribal community and to each consumer.

Innovation in Removing Barriers

"Necessity is the mother of invention" is a phrase that exemplifies the motivation behind many innovative programs throughout Indian Country. The personal diligence and leadership of individuals with disabilities and/or their family members have helped to reshape tribal communities and create more awareness, break down barriers, and push for expanded services and advocacy. Through their advocacy, tribal programs have realigned programs to create seamless services and more comprehensive support.

Effective Collaboration

A key factor for a successful program rests in the program's ability to effectively collaborate between agencies, programs, and funding sources. Those programs whose staff have extensive knowledge and awareness of other programs and services were able to develop the most comprehensive and innovative programs. All 10 of these tribes have demonstrated how their

creative collaborations increased the success of their programs in serving tribal members with disabilities.

Advocacy Strength

Advocacy is another key program success factor. Advocacy seems to be an inherent process of the work in Indian Country. It is a primary source of support for tribal members with disabilities who do not know how to or cannot advocate for themselves. Advocacy comes in many forms and is multidimensional. It is evident from the many voices of program leaders that it is essential to successfully serve people with disabilities.

Support from Tribal Leadership

Every tribal program included in this report noted that tribal leader support was an important factor in the success of the program. However, tribal leader support looked very different from tribe to tribe. Although not all tribes have laws protecting the rights of tribal members with disabilities, some have personnel policies and procedures, while other programs feel supported by their tribal leadership in some way.

Conclusion

Combinations of the elements identified from promising practices observed in existing programs seem to be aligned with comments by tribal leader Chief Joseph, Nez Perce: "The earth is the Mother of all people, and all people should have equal rights on it."

In the development of local policies, processes, and programming to serve and protect the rights of tribal members with disabilities, consideration needs to be given to the power of collaboration and an overarching awareness of local tribal culture. Unless programs are culturally responsive, consumers will not patronize the services offered to assist them. Knowing the consumer through meaningful inclusion in planning and hiring, and risking innovation in program designs to fit consumer needs, rather than attempting to fit consumers to program designs, are critical for success. Combined support from tribal leadership, committed and culturally responsive program staff, and positive results can realize enhanced empowerment for people with disabilities in Indian Country.

Federal Interviews

A series of interviews were conducted with federal and regional officials on government-to-government improvements. The selection of federal agency staff who were interviewed for this task was a joint decision, with input from the TEP. Three initial federal contacts were selected and then asked for additional suggestions of other officials to interview. This process led to the use of staff from headquarters and from regional offices in some agencies.

Ten federal interviews were conducted between September 15 and October 16, 2002. Interviewees included individuals who had management or operational responsibilities for AI/AN policies and programs within the following federal agencies: Administration for Native Americans, HHS; Administration on Aging, HHS; BIA, Department of the Interior; Department of Education; Department of Labor; IHS, HHS; and the Social Security Administration, HHS.

Discussion guides were developed and reviewed with the NCD project officer prior to the interviews with tribes and federal and state officials (see Appendix B). The discussion guides were used by the interviewer to focus the discussion, rather than as a formal questionnaire.

Department of Health and Human Services: Indian Health Service

IHS' Elder Care Program contributes to policy development and consultation with the tribes on issues affecting elders, including elders with disabilities.[106] IHS held a roundtable on elder issues in April 2002, and much of the discussion and focus of the meeting emphasized the importance of developing stronger linkages between the disability community and elders, since both groups are facing many of the same challenges in obtaining similar services.

IHS is working to develop mechanisms to support tribes in their development of support and programs to meet the needs of elders with disabilities. The approach is one that recognizes that tribal culture and understanding of disabilities are different from that of mainstream culture; tribes must develop culturally appropriate services and programs to meet their unique situations and preferences. The optimal approach is one that creates tribally controlled programs that are planned and developed by each tribe.

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[106] Interview with Dr. Bruce Finke, director, Elder Care Program, Indian Health Service, October 17, 2002.

The public health advisor involved with long-term care issues was interviewed for this study. She works closely with the Offices of Tribal Self-Governance and the Office of Treatment Activities.[107] With funding through these offices, tribes have a number of options: they can subcontract, purchase services, and/or provide services directly and pay salaries—such flexibility was touted as one of the strengths of crafting federal policy to match tribal environmental and political realities/needs. Moreover, this flexibility insulates tribes from having to "spend-down," when such action may not be in the best interest of effective program administration; they can also roll-over funds to the next year if necessary.

As a result of current funding mechanisms, the government-to-government relationship between IHS and tribes is well established. In 1975, the Indian Self Determination Act (P.L. 93-638) provided authority for tribes to contract and administer IHS programs directly.[108] More recently, federal law has allowed for increased flexibility for tribal contractors through a permanent self-governance program.[109] These two federal statutes provide a common point of reference and understanding that affirms the right of each tribe to determine if health services will continue to be provided through IHS or be administered through the tribe. In addition, frequent meetings between various IHS staff and tribes on funding issues and health services programming provide for enhanced interaction. One of the most significant stressors to government-to-government relationship is the unmet level of funding—a persistent undercurrent in almost any federal-tribal interaction.

The trend in CMS is to pay more attention to providing services on the reservation or at home. By fusing a series of resources together, some level of service often can be provided on the reservation. An example of interagency collaboration (and flexibility) that has worked well is the ability to pay family members to provide care at home. In an effort to sidestep internal barriers,

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[107] Interview with Lehoma Roebuck, public health advisor, Office of Public and Behavioral Health, Indian Health Service, September 27, 2002.

[108] Indian Self-Determination and Education Assistance Act, P.L. 93-638, 88 Stat. 2203, 25 U.S.C. § 450.

[109] The tribal Self-Governance Amendments of 2000, P.L. 106-260, 114 Stat. 711, August 18, 2000.

agencies initiate memoranda of understanding. These memoranda of understanding have proven successful in providing additional technical assistance and works to address/solve multiple agency issues at once. Having an interagency team go to council meetings to seek input would be very beneficial in terms of removing barriers.

Department of Education: Rehabilitation Services

The Department of Education's Office of Special Education and Rehabilitation Services Administration oversees formula and discretionary grant programs that help individuals with physical or mental disabilities obtain employment and live more independently through the provision of such supports as counseling, medical and psychological services, job training, and other individualized services. There are 10 federal regions with responsibility for RSA programs across the country.

Region X staff provide oversight and monitoring of programs in the states of Oregon, Washington, Idaho, and Alaska. In addition, Region X staff provide oversight, mentoring, and technical assistance to AIVRS programs across the country (of which there are only 69, even though there are more than 562 federally recognized tribes). By federal statute, American Indian rehabilitation programs function comparably to the state VR agencies; however, their services are provided to members of tribes who have disabilities and live on or near a reservation. The AIVRS grant application process is a competitive process; however, in keeping with their "community culture," tribal programs often share successful grant applications with new applicants for use as a template.

In 1996, RSA offered the assistant regional commissioner for Region X the opportunity to develop a technical assistance and mentoring program for all tribal VR projects. RSA provided him with time and a limited amount of money to cover costs to visit tribal VR programs and provide technical assistance and other support. In the first year, with cost containment in mind, he and his wife traveled in their motor home to 11 tribal VR programs in Montana, South Dakota, North Dakota, and Idaho. The agenda was based on two-day monitoring and technical assistance activities at each location.

Technical assistance was provided throughout the monitoring activities and was expanded to include meetings at each site with tribal council members, tribal VR staff, tribal colleges, state VR agencies, and client assistance program staff. The tribal VR agency directors were encouraged to invite state VR program staff and client assistance program staff to participate in two-hour meetings. The state agencies responded in 100 percent of the locations and in most cases it was the first time that state and tribal VR staff had met in the tribal communities and discussed common issues and coordination.

Department of the Interior: Bureau of Indian Affairs, Center for School Improvement – Special Education Programs

BIA's Office of Indian Education Programs (OIEP) receives funds through the U.S. Department of Education to provide funding for special education services in BIA-funded schools, of which there are 185 in 23 states. In addition, 14 peripheral dormitories receive BIA funding.[110]

BIA-OIEP awarded contract funds to 13 tribally controlled community colleges and state universities for the specific purpose of providing professional development opportunities for BIA-OIEP personnel and the provision of technical assistance and training to BIA-funded schools. This initiative is funded through the comprehensive system of personnel development requirement under the Individuals with Disabilities Education Act (IDEA) of 1997.

There is a general shortage of "certified" personnel in special education to meet the existing need. Special education is part of the continuum of services for people with disabilities. A primary element of the BIA mission for education is to provide and ensure that special education services are available to tribal school-age children in order to help them achieve academically. Professionals involved in that mission include physical therapists, speech therapists, counselors, and others.

All BIA-funded K–12 schools have schoolwide programs and are expected to provide an inclusive learning environment for all children; a priori planned placement separation between children with special education needs and other children is unacceptable. In accordance with the

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[110] Interview with Sherry Allison, Ed.D., director, Special Education Programs, Bureau of Indian Affairs, Center for School Improvement, September 27, 2002.

mandates of IDEA, BIA-OIEP submitted a Coordinated Services Plan for Special Education (CSP) to the U.S. Department of Education's Office of Special Education Programs. The CSP outlines a plan to coordinate services for children with special education needs at the local, regional, and national levels. Providers include vocational rehabilitation, Head Start, and tribal colleges.

Honoring Native American culture and language is an integral part of the school curriculum. BIA-OIEP has identified five general education goals, of which one is "students demonstrate knowledge of language and culture to improve academic achievement." Toward this end, BIA, through its state plan, requires schools to deliver at least eight two-curriculum units that address culture/language. Conversely, BIA does not require teachers in BIA-operated and/or BIA grant/contract schools to formally demonstrate their degree of cultural sensitivity. BIA-funded schools that are operated by individual tribes can make a determination about such a requirement individually.

Bureau of Indian Affairs – Division of Human Services

The Division of Human Services provides General Assistance (GA) to tribal members who are in need.[111] GA is a "secondary" program, available as an interim support program to people who have applied for TANF and are awaiting approval for services. It also provides support for people who are not eligible for TANF (e.g., single people without children). Under contracts/compacts, tribes operate 80–85 percent of the GA programs, with BIA regional offices providing oversight and monitoring. Within BIA, the Individual Indian Money accounts are the primary source of support for people with disabilities who have tribal trust monies. Tribal social workers or agencies evaluate and assess the needs of individuals with disabilities and determine whether they have special needs that require a wheelchair or other special equipment in order to hold a job or to maintain independence. This program is a source of funds to meet those needs and is flexible and specific to the individual's needs. The regulations have been in place for only a year and time has not been sufficient to assess effectiveness.

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[111] Interview with Larry Blair, director, Division of Human Services, Bureau of Indian Affairs, October 14, 2002.

Social Security Administration

The national lead for American Indian/Alaska Native Social Security Programs located in the Denver office was interviewed for this study. This person is involved in a number of activities designed to increase outreach, communication, and understanding of Social Security Administration (SSA) programs for American Indians and Alaska Natives.[112] In March 2000, SSA convened a national meeting to work with the tribes to identify strategies for better delivery of SSA programs to the AI/AN population. The Social Security Disability Insurance (SSDI) program was a major focus of that meeting.

As a result, SSA has developed several ongoing programs to better inform and assist American Indians and Alaska Natives. These initiatives include an interagency agreement with IHS and CMS. This agreement engaged the National Indian Council on Aging in piloting outreach to Indian Nations in New Mexico, Minnesota, and Montana. Results from the Montana Blackfeet Reservation suggest that these outreach efforts are helpful; over 100 people participated and 70 applications were completed on-site. SSA has also prepared a video titled "You and Social Security Disability," in which AI/AN people explain the SSDI program. The video was made, in part, in response to information that AI/AN people generally do not pursue SSDI enrollment if they receive a notice denying their initial application (regardless of the reason for the denial).

SSA is also developing a training package on Social Security and Medicare/Medicaid programs that will be provided to all SSA regions. This package, the result of the pilots conducted under the interagency agreement, will be useful in training benefit coordinators and community health representatives serving Indian Nations.

Administration on Aging's Native American Programs

The Administration on Aging (AOA) teams with the National Indian Council on Aging and other Indian organizations to provide training and technical assistance at national and regional meetings/conferences. Regional offices also provide technical assistance and on-site technical assistance every three years. In addition, the central office disseminates technical assistance

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[112] Interview with Richard Schremp, director, Electronic Service Delivery, American Indian/Alaska Native Social Security Programs, Social Security Administration, Denver Region, October 16, 2002.

briefs on an ongoing basis to tribal grantees. In the near future, AOA intends to fund an Indian contractor to provide technical assistance to Title VI programs.

The Title VI program works very well and a substantial comfort level has been established between federal program staff and the tribes. In part, this is due to the program's flexibility and the fact that AOA has consulted with and involved the tribes in developing the programs. AOA conducts national Listening Sessions with tribes to learn about and to identify areas for change and improvement. For example, tribes are allowed to define "elder" for the purposes of these programs.

In addition, AOA works closely with the National Title VI Association and with the National Association of Area Agencies on Aging to coordinate and collaborate on programs. AOA also administers Title VI, Part C, which provides family caregiver support services (the tribe must have a Part A grant to be eligible for Part C).[113] There are 178 Tribal Part C grants. The program permits meals to be delivered to people with disabilities who are not "elders."

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[113] Interview with Yvonne Jackson, Administration on Aging, Native American Programs, October 14, 2002.

SECTION IV

Government-to-Government Relationships: Findings and Recommendations

The major objective of this study was to develop a foundation of knowledge and information upon which to base specific government-to-government recommendations. Specifically, this section is provided (1) to identify barriers to effective federal-tribal government relationships and (2) to develop recommendations for improvements in government-to-government relationships. To accomplish these objectives, input was obtained from AI/AN people with disabilities (through the TEP), tribal leaders, tribal program administrators, and federal agency staff regarding their perceptions of these relationships and on strategies and processes that could be implemented to improve effective working relationships. The comments and recommendations from these interviews were considered and presented to two focus groups to determine if these are appropriate and reflect the concerns in Indian Country. One focus group was held at the National Congress of American Indians annual conference in November 2002 and included tribal leaders and AI/AN people with disabilities. The second focus group was held at the annual meeting of the Consortia of Administrators for Native American Rehabilitation, and included primarily consumers (AI/AN people with disabilities and VR program administrators). Based upon this extensive review by consumers, advocates, program specialists, and leaders in the field, the following government-to-government findings and recommendations are provided.

Findings: Barriers to Effective Government-to-Government Relationships

The barriers to effective federal-tribal government-to-government relationships were identified through the tribal and federal interviews. These barriers include

- **Fragmentation of services across federal agencies and offices.** Interviewees cited the fact that while a multitude of services are available, these programs and services are uncoordinated, and people with disabilities, and their advocates, are required to search for assistance with little assistance or advocacy to coordinate services. The complexity of seeking information and completing paperwork to obtain the full range

of services required is daunting and very time-consuming. Based on tribal and federal interviews, this factor is identified as a major barrier for people with disabilities in Indian Country where information and assistance to obtain these services is more limited than in other areas of the country. There is no "single source" within the Federal Government that tribes or tribal members can access to secure services, funding, or better understanding and resources to meet the needs of people with disabilities in Indian Country.

- **Lack of coordination and collaboration among federal, state, and tribal programs.** Since there are multiple overlapping programs, it is not always clear which government agencies have primary responsibility and which have secondary responsibilities or are the "payer of last resort." This is a particular problem for people with disabilities who live in Indian Country because, according to key respondent interviews and the review of literature, some federal and state agencies assume that IHS, BIA, or other federal agencies with responsibilities for AI/AN programs provide funds for all services to AI/AN people. This same lack of clarity is particularly a problem for federal programs that are operated through the states, since state agencies may assume that responsibilities for people in Indian Country are federal and that state programs do not need to serve tribes. The result may be that no one provides funding for some services. In addition, several reservations cross state borders, and tribal members may seek care in more than one state, adding to the difficulty in coordinating services and benefits.

- **Lack of federal personnel knowledge and training on the Federal Government trust responsibility to AI/AN people and on tribal sovereignty.** More attention and priority is needed at federal program levels to ensure adequate understanding and knowledge and to elevate the concerns of AI/AN people with disabilities. Lack of attention by program managers leads to an inadequate understanding of the federal trust relationship between the U.S. government and tribal nations. Many people in the Federal Government have limited understanding of the federal trust responsibility to

AI/AN people and/or the implications of tribal sovereignty. As a result, some programs may be designed inappropriately or not made available in Indian Country.

- **Lack of clarity about legal enforcement options.** The U.S. Supreme Court has yet to rule on whether and to what extent federal disability laws apply to Indian tribes. In the absence of such a ruling, different and sometimes conflicting opinions are being developed in lower courts. Federal laws designed to protect people with disabilities are not always enforceable against tribal governments because of the sovereign immunity and sovereign status that tribal governments enjoy. This does not mean that all other enterprises located in Indian Country are exempt from federal disability laws, only that tribal governments enjoy sovereign immunity. Many tribes have opted to adopt their own ordinances and codes to protect Indian people with disabilities within the tribal system.

- **Lack of involvement of tribal leaders and tribal members in the design, development, and implementation of programs.** Cultural and logistical issues require that effective programs to serve people with disabilities in Indian Country be designed and implemented to meet the unique needs and preferences of individual tribes. Many federal and state programs are designed from the top down and, as a result, may be inconsistent with the preferences of tribal members or with the structure of tribal programs.

- **Fear of the unknown and unfamiliarity with American Indians and Alaska Natives.** Federal key respondent interviews revealed that some federal agency staff are uncomfortable working with people from other cultures and are fearful of visiting tribal lands. This discomfort leads them to avoid meeting and interacting with AI/AN people and making visits to tribal areas where programs are operating. As a result, there is inadequate support and technical assistance to implement and effectively operate programs that serve people with disabilities in Indian Country.

- **Federal travel and budget limitations.** Federal headquarters and regional office staff members who administer or coordinate programs serving American Indians and

Alaska Natives face limited budgets for travel. Those who want to work with tribes to provide technical assistance, monitoring, and outreach related to programs for people with disabilities often are not able to obtain travel funds.

- **Historical distrust of the Federal Government by tribal leaders and members.** The Federal Government has a long history of not living up to its commitments to the tribes. In turn, tribal leaders and tribal members are distrustful and sometimes unwilling to work with federal agencies to develop and implement programs, particularly those that are developed without appropriate consultation with the tribes.

- **Difficulties in tribal/state relationships.** Relationships between tribes and states can be strained as a result of overlapping or conflicting jurisdictions and resource issues that may have nothing to do with disabilities. Tribes that are most successful at meeting the needs of people with disabilities in their communities have found ways to work with state programs. States may offer many services and programs that can be helpful for people with disabilities and their families living in Indian Country. It is important to remember that while tribes are sovereign governments, their members are also citizens of the state and of the United States and must be able to access state programs like any other citizen. Population statistics used by states to support funding for disabilities programs will also include AI/AN data, further adding to the justification for improved tribal access to state resources.

- **Limited consumer involvement at all levels of policymaking.** AI/AN people with disabilities and their advocates are not being consulted and involved in a meaningful way at all levels of tribal, state, or federal policy development. The participation of people with disabilities in the planning and implementation of appropriate policies, ordinances, programs, and services could make an important and meaningful difference for the quality of lives for people with disabilities living in tribal communities.

- **Failure to ensure that the national mandate to eliminate discrimination against individuals with disabilities included equal benefits for American Indians and Alaska Natives with disabilities.** In passing Title III of ADA, Congress announced the purpose as providing "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." Title III of ADA attempts to accomplish this goal by prohibiting discrimination in public accommodations. Unlike Title I, Title III does not provide an explicit exemption for tribal governments. Yet, there are limited means for enforcement of public access requirements against tribal governments, without a specific waiver of sovereign immunity by the tribe. Interviews with tribes indicate that accessible transportation is still the primary barrier for people with disabilities in Indian Country. Most tribal lands are located in rural and remote areas of the United States and lack public transportation systems, which could provide people with disabilities with access to transportation and increased independence. Tribes appear to be more concerned about roads and highways in Indian Country than with the need for public transportation systems within those same areas. Surveys of tribes found that one-third of the tribal and federal office buildings intended to serve the tribal communities are not accessible to people with disabilities (AIDTAC). Tribal lands and tribal communities may not have the infrastructure to support access and accommodation for people with disabilities, such as sidewalks and sidewalk ramps for wheelchair access. Federally recognized Indian tribes are specifically exempt from Title I of ADA, which prohibits discrimination against qualified individuals with disabilities in employment, and the requirement that employers make reasonable accommodation for employees with disabilities. This exemption is a barrier for Indians with disabilities in Indian Country, particularly in rural areas where tribal governments are often the largest employer. Some tribal governments have voluntarily complied with ADA or adopted their own codes to protect people with disabilities from employment discrimination; however, enforcement and local environmental changes to increase access, protections, and services are still far from meeting the national mandate described in ADA.

- **Advocacy made difficult by multiple education systems.** The majority (90 percent) of AI/AN children are educated by the public school systems in each state. The remaining 10 percent of Indian children are educated in tribally operated schools, or federally run schools of BIA. IDEA, funded by the Department of Education, requires both public schools and Interior-funded schools to provide children with disabilities with a free appropriate public education based upon an Individualized Education Program (IEP). Each child determined eligible for special education and related services must have an IEP team. Parents of children with disabilities in Indian Country may not be aware of the evaluation, services, and support their children are entitled to receive and may not know how to advocate for their children effectively. More parent advocacy training and on-reservation protection and advocacy services are needed for children and their families in both public school and BIA-funded school settings.

- **Limited tribal awareness and access to new strategies that can better serve people with disabilities.** Tribes are only just beginning to take advantage of the national trend toward increased home- and community-based services as a means to meet long-term care needs for people with disabilities, as opposed to institutionalized care, such as nursing homes. More states are providing Medicaid payments to cover these costs. However, studies show that AI/AN populations experience barriers to applying for Medicaid and Medicare eligibility, despite the fact that these reimbursements are representing a more and more significant part of the IHS annual budget. Access to affordable home- and community-based services can result in a significant quality-of-life adjustment for people with disabilities. Just getting out of bed, bathed, dressed, and out of the house can represent major barriers for some people with disabilities. Yet, with the support of a personal care attendant and other accommodations, many people with disabilities have become valuable members of the tribal workforce.

Recommendations to Increase Effective Government-to-Government Working Relationships

The vast majority of individuals interviewed throughout the investigation believed it was possible to improve the effectiveness of government-to-government working relationships, although some of the recommendations would require additional federal and state funds in order to implement them. The following findings and recommendations are a result of key respondent interviews, input from people with disabilities in tribal communities, findings from previous research, and feedback from focus groups.

Finding 1. Consultation: The majority of federal agency representatives stressed that programs should be designed and developed by the tribal communities, rather than top-down from the bureaucracy. Flexibility in program design and implementation was seen to be critical to the success of federally funded programs for AI/AN people with disabilities. Executive Order #13175 dated November 6, 2000, states that it will "…establish regular and meaningful consultation and collaboration with tribal officials in the development of federal policies that have tribal implications, to strengthen the U.S. government-to-government relationships with Indian tribes, and to reduce the imposition of unfunded mandates upon Indian tribes…." This Executive Order was reinforced by a letter from Alberto R. Gonzales, Counsel to the President, to Congressman Frank Pellone, dated June 19, 2002, in which Mr. Gonzales states that "In early 2001, the Bush Administration reviewed the Executive Order (13175) and found it to be consistent with the views of the Administration on tribal consultation and coordination. Currently, the Administration is working to see that the Order is implemented…." With regard to addressing issues of disabilities in tribal communities, this consultation has not happened in a comprehensive or meaningful way.

RECOMMENDATION 1.1: Formal government-to-government consultation needs to be initiated by the Federal Government in a way that will coordinate all the various federal agencies involved in issues of disabilities and tribal governments, and that involves tribal governments in the planning for these consultation sessions. The President's directive should identify a lead agency, such as the Department of Education, and require coordination among all the various federal agencies involved in issues of disability and

tribal governments. It should also require collaboration with tribal governments in a manner that involves appropriate representatives in planning for the consultation sessions.

RECOMMENDATION 1.2: The President's directive needs to clarify that existing tribal consultation plans should be reviewed at the agency level to ensure that each federal department identifies strategies for increasing meaningful discussions. The review should include plans for consultation around issues of disabilities prioritized in Indian Country and for expanding the participation of AI/AN people with disabilities in discussions and consultations.

Finding 2. Cultural competence, training, and orientation: Tribal and federal/state interviews revealed the importance of cultural competence, trust-building, and outreach when addressing the issues facing people with disabilities living in Indian Country. The improved understanding of tribal culture and of the federal responsibilities to American Indians and Alaska Natives is critical to developing positive working relationships that lead to effective programs. As one interviewee noted, "concerted, continuous efforts that include both initial outreach/consultation, and establishing a track record of 'follow through' is essential to developing a positive working relationship and to gain the trust of the tribes." National AI/AN organizations have established relationships with tribes and tribal leaders and can help overcome the historical distrust of the Federal Government. AI/AN organizations also bring to partnership efforts the depth of understanding of AI/AN culture and tribal structure that will facilitate and increase federal agencies' understanding and responsiveness to these issues.

RECOMMENDATION 2.1: Pursuant to the Executive Order on tribal consultations, a mandated, formal, and sustained education and orientation program that increases face-to-face interaction between federal officials and tribal officials should be implemented. The President's directive should require cabinet-level heads of federal agencies to ensure that orientation programs for all federal officials who administer programs for tribes or tribal members will be required by a certain date. Federal staff should plan to communicate and meet directly with tribal leaders, tribal program staff, and tribal people with disabilities on a regular basis. This ongoing contact will facilitate program flexibility and provide technical assistance to help tribal programs increase effectiveness. The more frequent

exposure of federal staff to tribal culture will also increase the comfort level of federal staff and strengthen positive working relationships. This exposure to tribal culture can occur effectively and in meaningful ways if sufficient travel funds and allocation of time are provided for tribal community visits. Such interaction should be mandated and monitored pursuant to the Executive Order.

RECOMMENDATION 2.2: Federal agency staff should be required to receive education and training about tribal governments and programs, the federal trust responsibility to tribes, an orientation on AI/AN cultures, and training on the unique challenges and opportunities faced by people with disabilities in Indian Country, if assigned to administer grants or contracts in AI/AN communities.

RECOMMENDATION 2.3: Consumer involvement must be increased substantially during the development of programs for people with disabilities in Indian Country. Tribal programs, state agencies, and federal programs must provide for meaningful consultation, involvement, and active leadership of American Indians and Alaska Natives with disabilities in addressing all needs assessments, planning, program implementation, and evaluation regarding the issues related to people with disabilities. To provide for effective consumer involvement, program budgets must include funding for travel and other accommodations.

RECOMMENDATION 2.4: Federal agencies should develop strong partnerships with existing national AI/AN advocacy organizations in order to develop culturally responsive strategies and approaches, to better address disabilities issues in Indian Country, and to conduct increased and more effective outreach and information dissemination campaigns. Specifically, agencies such as the Departments of Education, Interior, Health and Human Services, and Justice should convene an initial face-to-face working session and follow-up dialogue through scheduled telephone/video conferences. Joint strategy planning should be planned through the conferences with organizations such as the National Indian Health Board, the National Congress of American Indians, the Intertribal Deaf Council, the Consortia of Administrators for Native American Rehabilitation, and other grassroots entities.

Finding 3. Coordination and collaboration: The lack of coordination and collaboration among the various federal, state, and tribal programs charged with the responsibility of addressing the needs of people with disabilities is a significant barrier to improved services. There is a need to clarify responsibilities pertaining to the funding of services for people with disabilities in Indian Country among federal agencies and between federal programs and federally funded state-run programs.

RECOMMENDATION 3.1: Co-lead agencies, such as the U.S. Departments of Education and Health and Human Services, must be authorized to carry out the federal trust responsibility to provide culturally responsive information that raises awareness about protections and assistance to people with disabilities in Indian communities. Improved dissemination of information about programs that provide services to people with disabilities in Indian Country must be accomplished, and this information must be readily available to tribes, other federal agencies and staff, and state agencies and staff. This information must include clear descriptions of services, regulations, and responsibilities and could take the form of regularly issued newsletters, bulletins, a frequently updated Web site, or multiple communication media.

Finding 4. Recruitment and hiring of AI/AN professionals and advocates: Federal agencies do not demonstrate effective efforts to recruit, hire, and retain AI/AN staff within federally funded disability programs. Interviewees pointed out that federal data shows few AI/AN staff employed in the Federal Government, even in some agencies and programs that directly serve primarily AI/AN people. This fact may contribute to the finding that in some cases federal staff do not feel comfortable or competent when dealing with Native issues, including issues affecting AI/AN people with disabilities and their families.

RECOMMENDATION 4.1: The Federal Government must broaden its outreach efforts to increase the recruitment and hiring of American Indians and Alaska Natives. Specifically, the U.S. Department of Education's Rehabilitation Services Administration (RSA) should redirect a percentage of its funds for education grants to tribal colleges and universities for enhancing vocational rehabilitation studies. The Rehabilitation Act, Title III, Professional Development and Special Projects and Demonstrations provides RSA with the opportunity

for expanding efforts to improve conditions in tribal communities. In addition to its responsibility to oversee grants and to coordinate the vocational rehabilitation program and policy issues for American Indians and Alaska Natives within its agency headquarters and among its regional offices, RSA needs to recruit and hire people with extensive authentic experience both living in Indian Country and being actively involved with various types of AI/AN community affairs and cultural traditions as well as experience and knowledge about people with disabilities.

Finding 5. Application of federal disability laws: The degree to which Indian tribes are subject to federal disability laws is unclear within Indian Country. The Federal Government has a government-to-government responsibility to better inform its agencies and tribal governments with regard to the extent to which existing federal disability laws apply to tribal governments. This project looked at issues related to people with disabilities on "tribal lands," yet the legal jurisdictional issues have less to do with lands than with the sovereign status of tribal governments and the sovereign immunity of tribes. While rights and protections are provided in federal disability law, there is a lack in enforcement or lack of remedy for Indians with disabilities within Indian Country when those violations involve tribal governments or tribal enterprises.

RECOMMENDATION 5.1: In consultation with Indian tribes and AI/AN people with disabilities and their advocacy organizations, the Department of Justice, in cooperation with the Department of the Interior and with the participation of other relevant federal agencies, should immediately conduct an in-depth review of federal disability law as it applies to tribal governments, tribal enterprises, and people with disabilities who reside within Indian Country. A written report on findings of clarification should be provided to all tribes, Indian organizations, and disability advocate organizations.

RECOMMENDATION 5.2: The Department of Justice Civil Rights Division, in consultation with AI/AN people with disabilities and their advocate organizations, should convene a series of regional meetings to hear issues related to the application and enforcement of federal disability laws in Indian Country from both tribal and consumer perspectives. The Department of Justice should conclude these regional meetings with a

report on findings and recommendations to be disseminated throughout Indian Country and among other federal agencies.

Finding 6. Access to Independent Living Centers: AI/AN people are disproportionately underserved by independent living services. American Indian populations have the highest disability rate of any racial group in the United States and the least access to resources. As established under Title VII of the Rehabilitation Act of 1973, independent living services are to be provided to all people regardless of race, age, gender, or location. Services include information and referral; independent living skills training; peer counseling; and individual-based systems advocacy. Yet, only 3 of 350 federally funded independent living centers (ILCs) target services specifically to meet the needs of AI/AN populations. Expanding ILC services would represent the vital first step toward employment of people with disabilities.

RECOMMENDATION 6.1: The U.S. Department of Education RSA should provide a 25 percent set-aside of all funds available for ILCs. The funds should be allocated on a competitive basis for tribal communities to develop and provide ILCs for people with disabilities living in Indian communities. RSA should work to ensure that ILCs work cooperatively with all American Indian vocational rehabilitation services to ensure that appropriate independent living skills are developed before vocational rehabilitation occurs.

Finding 7. Access to vocational rehabilitation services: Tribal vocational rehabilitation services represent a potential starting point for increasing outreach and targeted services for AI/AN people with disabilities across Indian Country. Section 121 of the Rehabilitation Act of 1973 provides grants to governing bodies of Indian tribes located on federal and state reservations to assist American Indians and Alaska Natives with disabilities with vocational rehabilitation and employment assistance. Section 121 funding has been provided to tribes on a competitive basis, with limited opportunities to expand the total number of participating tribes. Currently, only 67 tribes out of a total of 560 federally recognized tribes receive federal funding from RSA. Many more communities warrant funding, and of those that receive funding, much more training, orientation, and technical assistance are needed to improve services for people with disabilities. While American Indian Vocational Rehabilitation Services (AIVRS) programs

have matured substantially, advancing their concerns through national meetings and sharing, additional funding stability and capacity building are needed.

RECOMMENDATION 7.1: The RSA Commissioner and the Secretary of the Department of Education need to agree to set aside the maximum amount in funding for Section 121 AIVRS programs allowable under law.

RECOMMENDATION 7.2: Future amendments to the Rehabilitation Act, which would allow for a substantial increase in funding set-aside and an allocation methodology developed in consultation with tribes to provide vocational rehabilitative support for all 560 federally recognized tribes in the United States, should be examined. There should be a planned expansion schedule of the AIVRS programs, increasing the amount of funds allotted each year.

RECOMMENDATION 7.3: In addition to funding tribal AIVRS programs, RSA should set aside funding for an ongoing national training and technical assistance project and to support field staff training and monitoring of the program.

RECOMMENDATION 7.4: RSA should revise its administration of AIVRS projects to show improvement in ways that promote the achievement of stability and sustainability in tribal communities. Once a program is funded, AIVRS should continue the funding based on objective criteria and indicators for program monitoring, evaluation, and appropriate technical assistance rather than requiring all to compete for continuation every five years. This new approach is similar to the funding process that supports the ILCs in section 722(e)(1) in the Rehabilitation Act. Each AIVRS project should receive at least a cost-of-living increase as per the Consumer Product Index each year, similar to programs under Titles I and VII. The President and Congress should develop legislative amendments to the statute to provide for continued funding of all the programs meeting performance standards. NCD should make this recommendation to the President and Congress in its annual report.

RECOMMENDATION 7.5: RSA should work closely with states to ensure improved results of efforts to comply with the provisions of the Rehabilitation Act in Indian Country.

This includes consultation with tribes and the inclusion of tribal members with disabilities in the development of state plans and commissions on rehabilitation. Results on a state-by-state basis should be reported to the public when each state plan is approved at the federal level.

RECOMMENDATION 7.6: Federal and tribal vocational rehabilitation programs should look more creatively at the possibilities of expanding employment of people with disabilities in Indian Country, including promoting the definition of employment outcome as stated in the Rehabilitation Act of 1973, as amended in 1998; to wit:

> **Section 7: Definitions (11) "The term 'employment outcome' means, with respect to an individual—(A) entering or retaining full-time or, if appropriate, part-time competitive employment in the integrated labor market; (B) satisfying the vocational outcome of supported employment; or (C) satisfying any other vocational outcome the Secretary may determine to be appropriate (including satisfying the vocational outcome of *self-employment, telecommuting, or business ownership,* in a manner consistent with this Act." (emphasis added)**

Finding 8. Access to home- and community-based services: AI/AN tribes rely upon the U.S. Indian Health Service (IHS) to meet their health care needs. These resources are drastically underfunded when compared with the average annual expenditure for all U.S. citizens or even when compared with annual expenditures for Medicaid recipients. For people with disabilities living in tribal communities, this lack in health care resources can mean the difference between life or death, independence or confinement. More and more tribal health programs are beginning to bill Medicaid and Medicare for services provided to eligible patients in tribal clinics. Opportunities to establish home- and community-based services (HCBS) for people with disabilities in tribal communities, financed through Medicaid or Medicare reimbursement, are developing.

RECOMMENDATION 8.1: IHS and the Centers for Medicare and Medicaid Services (CMS) should develop an initiative, in consultation with tribal governments, to expand training and technical assistance at the local level. They must also build HCBS in tribal communities to better serve people with disabilities. These training and technical assistance sessions should provide practical advice, manuals, toolkits, or other mechanisms to orient

tribal health providers in HCBS, funding or reimbursement opportunities, and strategies for including people with disabilities in the planning and design of these services. IHS and CMS should consult with AI/AN people with disabilities while developing and designing these training and technical assistance tools. In addition, regional or state-based meetings should be encouraged by IHS and CMS so that tribes and states can work together to plan and develop the services appropriate for each community.

RECOMMENDATION 8.2: IHS, Social Security Administration (SSA), and CMS should provide training for consumers, their families, and their advocates in Indian Country concerning the resources available to support improved health services and how to access appropriate long-term care services.

Finding 9. Social Security Administration liaison: One of the most significant barriers reported by tribal interviews was the rigidity and difficulty in working with SSA to secure either Supplemental Security Income for people with disabilities or Social Security Disability Insurance. There is significant dissatisfaction at the local tribal level with regard to administrative barriers that prevent access to these benefits. In many cases, these barriers could be based on a lack of cultural sensitivity and the absence of an effective Indian outreach approach by the agency.

RECOMMENDATION 9.1: The President should ensure that an Indian Desk is established at the headquarters level of SSA, the Department of Labor, and the Department of Education's RSA and Office of Special Education Programs specifically addressing needs of AI/AN people with disabilities.

RECOMMENDATION 9.2: An Indian liaison position should be established and filled in each of the federal SSA regional offices, providing outreach, technical assistance, and advocacy for the tribes and urban Indian organizations located in each of those regions. The positions should be filled by otherwise qualified people with the most extensive authentic experience living in Indian Country and active involvement with various types of AI/AN tribal community affairs and cultural traditions, including practical experiences and knowledge about people with disabilities.

Finding 10. Access to public transportation: Transportation was identified by our tribal interviews as one of the leading barriers for people with disabilities residing in Indian Country. The lack of accessible transportation for people with disabilities affects all other aspects of life, including establishing an independent living environment; attending school; and securing employment, housing, health care, and job training. The Federal Transportation Administration represents the largest source of funding in the United States for urban and rural transportation systems, yet in 1995 only 19 out of 560 tribes were receiving assistance through this resource. According to the Association of Programs for Rural Independent Living report in 1999, only 5 percent of transportation dollars were allocated to serve 27 percent of the population that lives in rural areas. The problem appears to be even more severe in tribal communities.

RECOMMENDATION 10.1: The Department of Transportation (DOT), in collaboration with other federal agencies, should set aside a more appropriate percentage of its funding to ensure that public transportation options are available in rural tribal communities. DOT should engage in a tribal consultation process, including discussions with tribal leaders and Indian people with disabilities, to develop specific strategies to increase accessible public transportation systems in tribal communities.

Finding 11. Employment opportunities: People with disabilities represent a valuable and underutilized asset for tribal communities seeking to develop a reliable and capable workforce. More education and awareness are needed among tribal officials and tribal program administrators to recruit, hire, and maintain people with disabilities in the tribal workforce.

RECOMMENDATION 11.1: Tribal governments and tribal programs serving people with disabilities should engage community and employer awareness programs in the development of employment opportunities for people with disabilities.

RECOMMENDATION 11.2: Tribal community colleges or other local educational institutions serving tribal communities should develop targeted outreach for people with disabilities in tribal communities to access education, training, and skills development to become substantial contributors to the tribal workforce.

RECOMMENDATION 11.3: Congress, with funding through the Department of Education, should provide the resources necessary to bring assistive technology to Indian Country that will increase the ability of people with disabilities to participate in daily activities, employment, and tribal government.

Finding 12. Public facilities access: Previous research has found that one-third of tribal and federal facilities located in Indian Country are not accessible to people with disabilities. This is a hardship for AI/AN people with disabilities residing in Indian Country, and a disincentive to other people with disabilities visiting or doing business in Indian Country. Tribal interviewees report that a major obstacle for tribes is the cost associated with retrofitting facilities to meet ADA accessibility requirements.

RECOMMENDATION 12.1: Congress, in the fulfillment of its federal trust responsibility and pursuant to the goals of ADA, should provide special funding for tribes to construct or retrofit tribal facilities and local federal infrastructure to maximize accessibility for all types of disabilities.

Finding 13. State and tribal relations: One of the major barriers preventing the expansion of services specifically targeted to meet the needs of people with disabilities in tribal communities is the tenuous relationship that has historically existed between tribal and state governments. Many of the programs and services needed to create a supportive network in tribal communities are administered through state agencies. Even though these programs are often federally funded programs, they are administered by the state, following a state plan and under the supervision of a state commission. While states have begun to recruit Indian consumer representatives to serve on the state councils or commissions, more collaboration is needed to leverage additional resources and services for Indians with disabilities in tribal communities.

RECOMMENDATION 13.1: The U.S. Department of Education's National Institute on Disability and Rehabilitation Research, RSA, and Office of Special Education Programs should provide a series of forums for dialogue in Indian Country. Therein, regional staff, state staff, and tribal members can discuss opportunities to work together to create partnerships for better serving and supporting the empowerment of people with disabilities

in tribal communities. Participants should identify strategies to ensure all citizens with disabilities are provided access to the same level of services, through service agreements and other cooperative arrangements.

Finding 14. Federal information dissemination: As articulated by Coria La Fontaine, a member of this project's TEP, "there are a lot of hidden disabilities and we need to make people aware of this…." AI/AN communities lack adequate resources to help raise awareness about disabilities, programs, protections, and services and to implement needed new programs and services for people with disabilities; they need the partnership, assistance, and funding of state and federal agencies. Any federally funded research should produce practical applications that can be implemented in Indian communities to improve the conditions of the people with disabilities studied. Considerable enthusiasm and anticipation have been generated by this NCD project in Indian Country, specifically with regard to the development of a culturally appropriate, user-friendly Toolkit for AI/AN communities.

RECOMMENDATION 14.1: Federal agencies that serve AI/AN communities, such as the U.S. Departments of Education, Interior, Justice, and Health and Human Services, should make a continuing and concerted effort to identify information appropriate for dissemination to those communities and make it readily available. Federal agencies should develop and implement strategies for culturally sensitive outreach and contacts with AI/AN tribes and individuals with disabilities. The NCD Toolkit developed by this project should serve as a resource and guide to federal agencies in their outreach efforts.

Finding 15. National gathering of key stakeholders: One theme that came through very strongly from discussions with federal and tribal staff was the need to "bring people together." Federal, state, and tribal people who get together to talk through common issues and problems will learn from each other and develop relationships that will provide a foundation for working together to improve programs and resolve problems facing people with disabilities. Organizations have emerged to support the self-determination and advocacy efforts of people with disabilities in AI/AN communities across the United States. It is important that these organizations have the support and encouragement from federal funding sources to collaborate

and convene, in partnership with organizations representing tribal governments, various forums to further address the issues raised in this report.

RECOMMENDATION 15.1: A federal initiative, with funding from multiple agencies, including the U.S. Departments of Education, Health and Human Services, Justice, Transportation, and Interior, should support the planning, coordination, and implementation of a National Summit on American Indians with Disabilities, gathering organizations such as the American Indian Disability Technical Assistance Center, American Indian Rehabilitation Research and Training Center, Consortia of Administrators for Rehabilitation, Intertribal Deaf Council, Commission for the Blind, and Native American Protection and Advocacy, in cooperation with organizations such as the National Congress of American Indians, National Indian Child Welfare Association, National Council on Indian Aging, and National Indian Health Board. The purposes of this summit would be to

- **Provide education and awareness on disability issues**
- **Provide education and awareness on disability law and its application and opportunities for tribal initiatives in tribal communities**
- **Provide a clearinghouse of information available to tribes**
- **Establish a legislative and federal policy agenda**
- **Interact with representatives of federal and state agencies**
- **Spotlight "best practices" in Indian Country**
- **Develop strategies for national advocacy**

RECOMMENDATION 15.2: An effective summit must include substantial participation by AI/AN people with disabilities. Any and all federal or tribal support for this summit should include a percentage of the budget allocated for "consumer participation," so that Indian people with disabilities can participate en masse.

RECOMMENDATION 15.3: This summit should not be a one-time event, but should be a recurring gathering, meeting at a minimum of every two years. This frequency is important

to sustain focused momentum and to ensure continued support for new leadership within the field of AI/AN disabilities. These summits should be repeated every two years in various regions across the United States under the sponsorship of multiple federal agencies, including the Departments of Education, Labor, Health and Human Services, Justice, and Interior.

SECTION V

Conclusion

AI/AN people with disabilities are among the most underserved and neglected populations in the nation. The high level of poverty among AI/AN populations; limited federal funding available for tribal communities for housing, education, or health care; and limited access to important infrastructure such as roads, sidewalks, and public transportation create a difficult and challenging environment for people with disabilities. Added to these socioeconomic challenges is the lack of clarity in Indian Country regarding the enforcement of federal disability laws that impact people with disabilities. Without the enthusiastic participation of tribal communities and tribal, state, and Federal Government representatives in closing the gaps between appropriate services and support received by the majority population and people from tribal communities, the level of disparity would be even greater. Yet, underserved and unserved people with disabilities among AI/AN populations face an uncertain and bleak future in terms of obtaining equal opportunities, independence, inclusion, and freedom from discrimination. Effective collaboration between sovereign governments is key to successfully addressing the issues and needs of tribal members with disabilities and descendants living in Indian Country. Emphasis must be placed on the building of relationships between all stakeholders. American Indians and Alaska Natives with disabilities must be invited to the table in key conversations regarding policies, initiatives, program development, and resource allocation.

Where do we go from here? In the spirit of self-determination, Andrea Siow (Hopi Nation), TEP member, stated, "By getting the word out that people with disabilities are not helpless, we can create awareness and improve things....It is up to us to find our path...." Self-determination is fundamental not only from the perspective of tribal government, but from the view of the individual tribal member with the human need for opportunity, inclusion, support, access, and freedom to chart one's own course. This nation's mandate to eliminate discrimination against individuals with disabilities has thus far failed to appropriately address the inclusion of AI/AN communities. For people with disabilities in these communities, the freedom to fulfill their dreams, access economic independence, and meaningfully participate in their tribal community

may rest in the willingness of tribal, state, and federal governments to work together, cooperatively and effectively. Ultimately, this will need to be accomplished in ways that will achieve the Congressional intent of disability laws and will fully respect this nation's historic legal obligations to tribal governments.

Collectively, the traditional leaders can look to tribal people with disabilities as key among the stakeholders who can change the current environment in ways to reach all unserved and underserved people across this great nation. Many small tribal nations, a good deal of which do not possess the adequate economic base needed to fully accommodate, protect the rights, and serve the unmet need of tribal members with disabilities, comprise the majority of Indian Country. Federal, regional, and state program leaders must seriously consider and commit to expanding the necessary financial resources. The time for these leaders to establish opportunities for dialogue and begin building collaborative working relationships with tribal governments and people with disabilities is now. In the words of Steven "Corky" West (Oneida Nation), "the consumers are the leadership. Learn from the consumers."

APPENDIX A

The Technical Expert Panel

Azure, Mark

Tsimshian/Hunkpapa Lakota

Intertribal Deaf Council

Consumer

Clay, Julie Anna, M.P.H.

Omaha Tribe

Training and Dissemination Coordinator

American Indian Rehabilitation Research and Training Center (AIRRTC)

Consumer

Davis-Wheeler, Julia

Nez Perce

Tribal Leader

Nez Perce Tribal Council

Chair, National Indian Health Board

Fowler, LaDonna

Turtle Mountain Chippewa Cree/Santee Sioux/Assiniboine

Chairperson, Subcommittee on Disability, National Congress of American Indians

Co-Founder American Indian Rehabilitation Rights Organization of Warriors (AIRROW)

National Board Member, AIRRTC

Secretary, Multicultural Committee, National Council on Independent Living

Co-Secretary, Native American Alliance for Independent Living

Charter Member, Cultural Diversity Advisory Committee for National Council on Disability

Native American Disability Consultant/Consumer

Francis, Joanne

Akwesasne Nation (Mohawk)

International Disability Consultant

Consumer

Garcia, Joseph

Prairie Band of Potawatomi

Board Member, American Indian Disability Technical Assistance Center

Student, Salish Kootenai College

Consumer

LaFontaine, Cordia

Consumer

Locust, Carol

Eastern Band Cherokee

Indian Health Services Health Consultant/

Cultural Sensitivity Trainer and Consultant

Consumer

Lucero, Danny

Navajo/Apache Nations

Vice President, Intertribal Deaf Council

Gallaudet University

Consumer

Miles, David J.

Nez Perce Tribe

Director, Nez Perce Vocational Rehabilitation Services

Board Member, Idaho State Independent Living Council

Board Member, Idaho State Rehabilitation Council

Paris, Damara

Cherokee

President of the Intertribal Deaf Council

Consumer

Siow, Andrea

Hopi Nation

Miss Hopi Nation

Consumer

Smith, H. Sally

Tribal Leader

Executive Committee, Alaska Native Health Board

Executive Committee, National Indian Health Board

Williams, Raho

Navajo Nation

Independent Living Specialist

San Juan Center for Independence

Consumer

Windy Boy, Alvin

Chippewa-Cree

Tribal Leader

Rocky Boy Reservation

APPENDIX B

Interview Guide for Discussions with Federal/State Agency Staff

Interviewer will briefly summarize the study and objectives of the interview and discuss/answer any questions that the interviewer may have.

- What are the responsibilities of your agency/office with respect to providing funding, services, and/or protections to people with disabilities in Indian Country?
- How do you and others in your office work with tribal governments? particularly on issues affecting people with disabilities?
- Are these government-to-government relationships well established? What are the processes for working with tribal governments?
- Do these processes work well? What are some of the factors that contribute to the effectiveness of your programs, policies, and procedures? Can you provide examples of effective processes?
- Do you have examples/evidence of "promising practices" (within your agency or others of which you are aware) that seem to work well to benefit people with disabilities in Indian Country?
- What types of "outreach" efforts does your agency have in place to improve services and programs to American Indians/Alaska Natives in Indian Country? nontribal areas? for people from any other diverse cultural/ethnic/racial groups?
- Within your agency, are any programs, training, or policies in place to address cultural competency in implementing/monitoring/enforcing laws and programs and services?

- Are you aware of any problems or difficulties that have occurred between your office and tribal governments, when the processes in place have not worked well? Can you provide examples?

- What are the barriers/difficulties you or others in your office have encountered in developing and maintaining effective government-to-government relationships? examples?

- Are you aware of any innovative approaches or strategies (within your agency or others) that have helped to develop and maintain effective government-to-government relationships?

- What changes would you like to see made (within your agency or others) that would result in improved services and programs to assist people with disabilities who live in Indian Country? to assist American Indian/Alaska Native people with disabilities, wherever they may live?

- What suggestions or recommendations do you have that would improve communication and collaboration among federal/state/tribal governments on issues that would improve support and services to people with disabilities in Indian Country?

APPENDIX C

Interview Guide for Discussions with Tribal Programs

1. Does your tribal government have a law or resolution that prohibits discrimination against people with disabilities and requires equal opportunities for people with disabilities?

   - If no: How does your tribe protect rights and opportunities for people with disabilities?

   - If yes: What were the key elements or factors that convinced this tribe to develop tribal laws, ordinances, or codes to protect and meet the needs of people with disabilities?

2. How does your tribe address support services for persons with disabilities and their families, such as home support programs, respite coverage for parents, personal care attendants, and other caregivers?

3. What are the major barriers for people with disabilities on your reservation?

4. Describe how people with disabilities access health care in your tribal community. Who are the health providers most likely to see and understand the needs of people with disabilities?

5. What are the barriers to health care experienced by people with disabilities in your tribal community?

6. Are children with disabilities treated differently in your school systems? Please describe.

7. What services (supported employment, transportation assistance, job coach) for employment for people with disabilities come from inside your tribe? outside your tribe?

APPENDIX D

Case Studies of Three Tribal Communities

Introduction

The following case studies provide additional insight into the approaches used by three tribal communities and a federal region—Confederated Salish and Kootenai Tribes, Hopi Nation, Oneida Nation, and federal Region X—to address the needs of people with disabilities on tribal lands. The three communities were selected from the 10 tribes interviewed for this study. They were selected because their level of tribal government commitment to taking actions and changing the attitudes and environment of tribal communities with regard to providing improved access and services for people with disabilities stands out. The results for people with disabilities have been improved services to individuals and families and enhanced support for self-determination efforts. The case studies are summarized below:

Confederated Salish and Kootenai Tribes

The Flathead Reservation, home of the Confederated Salish and Kootenai Tribes (CSKT) in western Montana, spans 1.5 million acres in seven communities.[114] The reservation is largely divided between tribal and non-Indian ownership. The local county population is approximately 22,000—and of that population, only 4,000 are tribal members. This means that the CSKT are the minority on their own reservation. This creates great challenges when faced with an environment of racial discrimination. In the town of Ronan, 51 percent of the students are American Indian, and only 4 to 5 percent actually graduate from high school. In addition to tribal members and non-Indian landowners, the Flathead Reservation is home to a high count of 2,600 American Indians from other tribes. The local tribal college draws many other Indian people into the territory.

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[114] Templer, Arlene. Confederated Salish and Kootenai Tribes. Telephone interview by Martina Whelshula. December 19, 2002.

There is a 41 percent unemployment rate year-round, with winter having the highest rate. CSKT is the major employer on the reservation, employing approximately 1,200 people in the summer months and about 700 in the winter months. There are many who also depend on the timber industry, which has been difficult since the fires in 2000; tribal revenue is down since then. Other employment opportunities include farm work, odd jobs, and small businesses.

CSKT Collaborative Programming

Since the late 1990s, the only referrals for vocational rehabilitation came from other tribal departments. Staff came to realize that many Indian people do not see their disability as an "issue." It was part of their journey in life, and a person needed to learn how to deal with it. The term "disability" is not in either the Salish or Kootenai languages. Staff had to explain to people that their disability met the criteria to qualify them to receive disability services. The positive results associated with the vocational rehabilitation program at CSKT may be attributed to three key elements. The first is people who know the systems and services that can assist people with disabilities. The second key element is awareness of different perceptions of the term "disability." The third key element is outreach and coordination across several programs to ensure services and people are connected.

The vocational rehabilitation program is 17 years old. It used to be based in the tribal college and was known as a program for college students. CSKT removed it from the college in 1998 to provide services to the whole reservation. The way it carries out a "one-stop shop" model is the program's strength. A strong relationship with department heads led to building programs simultaneously and providing access to many other programs that serve consumers. Program leaders report that they recognize the benefits of knowing about various grants and programs, and of building positive working relationship. The vocational rehabilitation program serves the entire reservation, making collaboration critical to consumer success. There are satellite offices in Mission, Ronan, and Polson. The number of people served by the vocational rehabilitation program range from 80 to 110.

Benefits are coordinated to expand the services for tribal members with disabilities through the CSKT One-stop Shop. How does this work? As one example, a family served by the tribal Temporary Assistance for Needy Families (TANF) program would have an Individualized

Family Plan for Employment developed and then utilized to fulfill the work requirements for TANF. The consumer would obtain cash assistance from TANF for living expenses and vocational rehabilitation funds for specific training needs only. The CSKT vocational rehabilitation and Adult Basic Education staff members work together frequently to help people get their general education diplomas and obtain learning disability testing. Vocational rehabilitation staff members also ensure that the consumer is having basic needs met through food stamp and commodity services. The food stamp office is next door to the vocational rehabilitation office. Childcare is provided through a block grant to provide daycare services during work-related activities for parents. Vocational rehabilitation staff members also work closely with a job specialist, the tribal Department of Human Resources, and On-the-Job Training to secure job placements for consumers with disabilities.

CSKT tribal staff members for different programs were once described as a lot more territorial—working alone rather than collaborating across programs—until the CSKT Tribal Council placed everybody in one department. Public Law 102-477—commonly called 477—provides Indian tribes with the option to integrate their federal employment, training, and childcare funds into one consolidated budget and program. The 477 option also allows tribes to consolidate reporting requirements for these various federal programs, reducing paperwork and streamlining services. Although the CSKT vocational rehabilitation and the Women, Infant, and Children's programs are not included in the 477 contract, these programs are coordinated with the other employment, training, and childcare opportunities. A positive outcome of coordinating these services is that people with disabilities can access assistance through a seamless program, resulting in improved and more comprehensive services.

CSKT Transportation Services

In addition to the collaborative service delivery, there has been opportunity to focus on a number of barriers facing people with disabilities. Program staff members developed ways for transportation resources to connect tribal members to employment opportunities. Transportation has been identified as a leading barrier for the CSKT. Remoteness and isolation are primary barriers for the community as well. Many tribal members are as far as an hour away from the tribal complex and tribal health and human service offices where the majority of services are

provided. Transportation needs were integrated into vocational rehabilitation, elderly, and independent living grant proposals. In this way, a resolution to the barrier became part of the process of strengthening existing services. The transportation program uses a number of approaches, yet recognizes challenges to the implementation of the program. Use of a transportation voucher system is a limited option because of the lack of availability of licensed drivers with automobile insurance and the fact that there are few service providers to receive the voucher. In an attempt to find a solution to this problem, workshops are provided to help people get their driver's license. An additional barrier is that the closest cities in which to obtain driver's licensing are Missoula and Kalispell, and they are both about one hour away. The CSKT co-authored a grant with Missoula's Rural Transportation Department, If the reservation has buses, they can link at Missoula.

The significant impact of the transportation problem has led to seeking a more long-term resolution. Using accessible buses, vans, and cars, the vocational rehabilitation staff members are developing a combination fixed-route dispatch service in collaboration with the Salish Kootenai College. The CSKT's approach to meeting the transportation need has been to integrate services and to seek technical assistance through a network of partnering agencies. By taking a two-pronged approach, the tribe is able to offer temporary transportation services to supplement vocational rehabilitation, elderly services, and services for individuals with disabilities while working to develop a more comprehensive service that is tailored to its community's specific need.

CSKT Education

Many CSKT members have not received a lot of education. This is apparent when testing shows they do not have the knowledge to pass tests. A vocational rehabilitation leader Ms. Arlene Templer (CKST) has begun work with the schools in all six districts on the reservation. The local Bureau of Indian Affairs school provides—and pays for—disability services to the children attending. In working with the other school districts, the vocational rehabilitation leader assists with development of an Individualized Education Program for students beginning at age 14. She goes to the schools as a tribal and vocational rehabilitation representative and tells students about resources available to them as Indian people. She provides them with transition kits (packets)

that include information on a variety of different resources and programs, such as the tribal Department of Human Resource Development, Salish Kootenai College, and Job Corps, and a letter from the tribal chairman encouraging students to finish their education.

CSKT and State-Level Collaboration

Ms. Arlene Templer, the vocational rehabilitation leader whose activities were described above, now chairs the Montana State Rehabilitation Council after a year as vice chair. She stays up-to-date on grants made to the state and develops proposals for grants to the tribes. She is uniquely positioned to know about state and federal grant dollars. The Section 121 regulations mandate tribal representation on state rehabilitation councils. The State of Montana conducts consumer surveys to determine satisfaction with state programs and services. Along this line, Ms. Templer has asked the state to survey a tribal program and suggested CSKT as the pilot program. She indicated that she feels comfortable enough with the program to recommend it. Both located in Montana, the American Indian Disability Technical Assistance Center and the Rural Institute on Disabilities are attempting to assist in program development across Indian Country in the state, enhancing services in self-employment, among other services CSKT consumers access.

CSKT Lessons Learned

It is important to network with service providers, agencies offering grants, and technical assistance organizations in order to understand the service options and funding available to the community. In addition, a program could consider integrating transportation services with vocational rehabilitation and job employment, education programs, elderly services, and disability services.

Hopi Nation

The Hopi Reservation is located in northeastern Arizona. It occupies about 2,439 square miles. The tribal population is approximately 11,000, with 8,000–9,000 tribal members residing on the reservation.[115] The reservation lies 92 miles northeast of Flagstaff and 50 miles north of Winslow. The Hopi people reside in 12 villages throughout three mesas, including two villages

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[115] Talaswaima, Rhonda. Hopi Nation. Telephone interview by Martina Whelshula. December 26, 2002.

located 45 miles west of Third Mesa. The village of Kykotsmovi is home to the Hopi tribal government headquarters. The size of the population of each village determines the number of council seats. However, not all villages have representation; some choose to practice their traditional form of leadership and governance. The council is composed of both male and female representatives.

The Hopi are a closeknit matrilineal people with strong extended family and clan relationships. They are by tradition farmers and practice dry farming. In addition, the Hopi are a nongaming tribe, choosing not to participate in this economic venture for philosophical and religious reasons.

Hopi Office of Special Needs

The Hopi Office of Special Needs includes the early intervention program and the newly awarded vocational rehabilitation program. Their office serves tribal members residing on the Hopi Reservation. The program director attributes the success of the program to tenacity and motivation. The establishment of the Office of Special Needs all started with a parent group with the determination and dedication to make a difference.

Success is enhanced through networking with other tribal programs within the tribal organizational structure. The tribal personnel department supports the program's efforts and assists in the hiring and orientation of tribal members with disabilities. Staff at the Office of Special Needs is aware that any kind of change takes time and should be approached "one step at a time." Staff report that the Hopi philosophy addresses disability with the basic belief that all people have value and worth. Tribal departments typically support efforts of the Office of Special Needs to serve tribal members with disabilities through concerted efforts to comply with any requests made for assistance.

Hopi State-Level Collaboration

The Hopi early intervention program is provided with technical assistance through the state. In addition, staff members for the new vocational rehabilitation program are working with the state staff to finalize a cooperative agreement for providing services to consumers. Tribal staff members report a positive relationship with state counterparts and work collaboratively to

expand services. They also report that working cooperatively with other resources results in people with disabilities being provided with better and more comprehensive services.

The director of the Office of Special Needs, Mrs. Rhonda Talaswaima, was appointed by the state governor and is the only Native American to sit on the Arizona State Governor's Council for Developmental Disabilities. She was also involved with Partners in Policymaking, a leadership program developed to empower consumers and parents of individuals with disabilities to make systemic changes in their communities. Staff members report it was an opportune time to network and make a difference in the state. According to Mrs. Talaswaima, who believes in demonstrating initiative, people need to be supported in becoming empowered to believe that they can make a difference.

The director of the Office of Special Needs also serves on The Institute of Human Development's Community and Consumer Advisory Committee at Northern Arizona University. The role of this organization is to review different issues and priorities affecting people with disabilities. In addition, Hopi is one of the first tribes in the State of Arizona to participate in the Department of Economic Security (DES) Advisory Council. This council provides an opportunity for Hopi people to discuss specific issues related to DES programs on the reservation, including programs dealing with individuals with disabilities.

Hopi Lessons Learned

Tribal staff members report that dedicated employees who share a vision of improving the lives of individuals with disabilities are key to creating a better environment in reservation communities. Demands upon the time and commitment of staff are significant, and the Hopi Tribe has addressed this by building a strong foundation of understanding, vision, and participation in leadership. Staff members also report that while funding is important, of more importance are staff who work hard to provide options and resources in the lives of people with disabilities. The Annual Hopi Special Needs Activity Day attracts over 600 people from reservation communities. This turnout is significant, according to tribal staff, and can be linked to the staff's level of outreach and enthusiasm. Another key to improving the reservation environment for people with disabilities is the ability of tribal staff to network throughout the larger state agencies and leverage new resources and support.

Oneida Nation

By tribal constitution, direction for the Oneida Nation is provided by a General Tribal Council (GTC) that must meet a minimum of two times per year.[116] The GTC includes all of the voting-age enrolled members. At GTC meetings, the general direction for tribal operations is established. That general direction is carried out and further defined by the business committee, which is a nine-member panel that includes four executive officers and five council members who are elected at-large. The business committee is also responsible for administration of the day-to-day operations of the tribe and its programs, services, and affairs.

The Oneida Nation has nearly 15,000 tribal members with, according to the 2000 census, roughly 7,600 living on, or adjacent to, the reservation in Brown and Outagamie Counties. The census figures may be skewed in that respondents who self-identified as American Indian may include tribal affiliations other than Oneida. The data indicates that another 2,000–3,000 Oneida live in Milwaukee, Chicago, and other urban areas. Surprisingly, a significant population of Oneida lives in California because of relocation.

The Oneida Reservation spans 56 square miles and lies diagonally in Brown and Outagamie Counties, along a northeast-southwest axis west of the Fox River in northeastern Wisconsin. The reservation is "checker-boarded" with tribal and non-Indian land ownership. A large portion of the reservation lies within the city limits of Green Bay, Wisconsin. The Oneida Reservation can be classified as an "urban" reservation. This creates a great advantage in accessibility. Yet the Oneida are faced with frequent intercultural-interracial relationships. These can be rocky or they can be smooth. There exists a subtle racial discrimination among some members of neighboring communities, but it does not manifest often. The Oneida Nation and the City of Green Bay, along with other neighboring communities, generally have a positive working relationship.

Diversified business development is building gradually for the tribe. Among the tribal businesses are a hotel/conference center, a printing business, a casino, smoke shops, a cooperative food store, and a communications corporation. Their largest revenue producer is gaming. Prior to

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[116] West, Steven "Corky." Oneida Nation. Telephone interview by Martina Whelshula. January 2, 2003.

gaming, there was not much business or revenue. The Supreme Court case *Bryant vs. Itasca* opened the door for smoke shops and retail gasoline outlets (One-Stops). These smoke shops and One-Stops became a significant source of revenue for the tribe.

The primary coordinator for service to people with disabilities is the director of the Tribal Vocational Rehabilitation Services Program. The 1998 amendments to the Rehabilitation Act made it possible for Oneida and other tribes in Wisconsin to be involved under Section 121 of the Rehabilitation Act. Previously the Oneida Nation had provided similar services through the Job Partnership Training Act (JTPA). The Oneida received their initial vocational rehabilitation services grant in 1998.

Finding Hopi Supports and Overcoming Attitude as a Barrier

The tribal staff reported that many JTPA participants who received training services were repeatedly coming back for the same types of services. Staff observed a pattern emerging that those without cognitive or emotional problems were the only ones benefiting from conventional job training services. It was realized that the problem was not the individuals' intent or motivation. Cognitive or other disabilities appeared to affect client ability to handle job training and key life issues. Tribal staff identified the need for supplemental services for some consumers in the program and put these consumers in contact with other directed rehabilitation resources. This move has increased participation in the Oneida program 10-fold. The state served 16 Oneida people in one year prior to Oneida receiving the vocational rehabilitation grant. Since then, the Oneida program has served 180 consumers in approximately three years. The Oneida program has a cooperative relationship with local employers. One of the greatest needs has been to help people get motivated and job ready.

Members of the tribal staff report that one of the barriers is the tendency for service providers to perpetuate dependency, which can lead to learned helplessness. In a dependency mode the tribe is looked to for all tribal consumer needs. Staff report that changing the system is a slow process, and they are working so that both consumers and the tribe change their way of thinking. The members of tribal vocational rehabilitation program staff are working to create interdependent models that provide opportunities for creating choices and eliminating barriers for people with disabilities.

When the counseling staff works with an individual with a disability, a team is formed. The team is made up of a counselor and other human service professionals who share case management. In the past there did not seem to be any communication on coordination of services and one program would not be aware that a consumer was receiving other services such as mental health counseling. This lack of coordination would inevitably create a conflict in which one program would develop an Individual Plan for Employment (IPE) that was in conflict with the mental health program. These programs now work together and IPE are developed that parallel treatment plans. They may even "piggyback" appointments. The One-Stop Job Center, which the Oneida have created under the Workforce Development Act, improves communication between the multiple service provider partners and the consumer while developing closer working relationships. This translates into a better delivery system shifting the responsibility to the consumer.

Oneida Nation and Wisconsin State-Level Collaboration

The tribe's vocational rehabilitation director currently serves as chair of the Wisconsin State Independent Living Council. The state council annually sets aside funds for requests for proposals for outreach to underserved populations such as tribes. All independent living centers (ILCs) in the state that serve tribal populations are provided with supplemental funds if their proposals show that the supplemental funds can enhance delivery of services to tribal populations. Wisconsin is the first state to have all of its ILCs federally funded. Mr. Steve West (Oneida Nation) was appointed to the state ILC as a result of the 1998 Rehabilitation Act amendments. He reports no problems from the state's side with the 1998 amendment. This is the amendment that mandates that Section 121 programs should be represented on the state ILC and rehabilitation council. The governor of Wisconsin appointed the tribal vocational rehabilitation director, who also serves on the regional Workforce Development and the Governor's Manpower Planning Boards. The director also actively serves on the Consortia of Administrators of Native American Rehabilitation executive board as treasurer.

Oneida Nation Funding Options

The Oneida Nation made their annual payment of $4.8 million to the State of Wisconsin in January 2003 from tribal gaming revenues in accordance with their agreement (compact) with the

state. The compact allows the tribe to designate where these funds are spent. Tribes supported a request from the state vocational rehabilitation agency to make funds available for the purpose of matching additional federal dollars under Title I of the Rehabilitation Act. The state legislature agreed and allocated $350,000. These dollars supplement vocational rehabilitation activities and made it possible to create two full-time counselor positions in urban Milwaukee. This compact also serves to supplement projects such as the Great Lakes Inter-Tribal program (covering nine tribes). This strategy helps save vocational rehabilitation funds for use in providing other direct services to all people with disabilities across the State of Wisconsin.

Oneida Nation Lessons Learned

The experiences of the Oneida Nation vocational rehabilitation staff indicate that one key lesson is to focus on changing the attitudes among tribal leadership, tribal staff, and consumers about fostering independence and reducing dependence as a universal goal. Another key lesson was the importance of program coordination among tribal and state resources and case management in providing effective services and long-term employment for people with disabilities. Finally, the experience at the Oneida Nation further underscores the impact of strong leadership at both tribal and state levels on the creation of new funding and programming opportunities to better serve people with disabilities in tribal communities.

Rehabilitation Services Administration – Region X

The Region X Rehabilitation Services program has a person with involvement in tribal affairs and cultural traditions serving as rehabilitation services specialist. Others have described her sharing intimate knowledge of tribal government and federal and tribal barriers as particularly helpful to American Indian Vocational Rehabilitation Services agencies and Rehabilitation Services Administration staff.[117] Monitoring of and technical assistance to the American Indian vocational rehabilitation programs were sparse because of budgetary needs until during the 1990s, when despite budgetary restrictions, limited technical assistance and monitoring became available thanks to the personal commitment of the assistant regional commissioner for Region

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[117] Interview with Department of Education: Region X Rehabilitation Services Specialist, September 27, 2002.

X. He conducted recent onsite visits in California, Oregon, Arizona, New Mexico, Colorado, Wyoming, and Oklahoma, as well as revisited sites that were visited in previous years.

Region X Lessons Learned

Among the many lessons learned from this regional experience was the importance of cultivating and displaying positive leadership qualities at the federal level. Perseverance, commitment, innovation, and inclusion were among the leadership qualities reported as important regarding the way Region X staff worked with tribal leaders and people with disabilities across the affected tribal entities. Region X actions demonstrating these and other leadership qualities, such as the ability to lead by example, to "smooth the way," and to demonstrate commitment, raised the consciousness of other people about the needs of the American Indians with disabilities. Other demonstrations of effective leadership were noted in accounts of culturally sensitive personal contacts with tribal councils and tribal leadership to assist in the understanding of vocational rehabilitation programs and the potential benefits for tribal members.

APPENDIX E

Observations of Community Leadership

In the course of interviewing the tribes, it became increasingly evident that the program took on the qualities and characteristics of its leadership. Common elements shared by each program director were as follows:

- **Passion**

  Each of the program directors demonstrated this trait in thoughts shared and actions taken. The passion was conveyed not only through descriptions of the programs and services delivered, but in the difficulties many programs transcended over time.

- **Perseverance**

  In the face of many challenges and obstacles, the program leader's belief in the work helped individuals to keep moving and fighting for changes when the task seemed almost impossible.

- **Vision**

  Each program leader believed in the possibilities for change in tribal communities in ways that improve the provision of disability services and seemed to have mental pictures and plans that were demonstrated through unique or innovative approaches to addressing the gaps in services for tribal members with disabilities.

- **Commitment**

  The majority of program leaders had been with the program for several years and were determined to create change to improve the quality of life and services for tribal members with disabilities.

- **Change Agents**

  These program leaders pushed for creative and different ways of doing things that sometimes made them unpopular with others favoring the status quo.

- **Consistency**

  Program leaders who stayed with their programs for many years provided a sense of reliability, stability, and consistency. The element of consistency nurtured the sometimes slow process of growth that also occurred in ways that built upon the many lessons learned through the years.

- **Connection to Consumer**

  These program leaders strive to know their consumers despite some complex circumstances and multiple variables surrounding programs.

- **Agents of Hope**

  Many of the conditions surrounding the whole issue of disabilities in Indian Country are severe enough to leave consumers and advocates with a sense of hopelessness. Some program leaders have described the bleak realities of tribal members with disabilities. In the face of some desperate conditions, these program leaders try to embody a positive sense of hope, inspiring consumers to hang in there; change is coming.

Most program leaders who were interviewed for this report will tell you that they hold only one part of the total effort needed to improve the quality of life for tribal members with disabilities. The leaders described the many people, including tribal people with disabilities, who have contributed to the success of effective programs and the services. Humility was apparent as leaders expressed excitement at how segments of their tribal communities fought long and hard for change that resulted in improvements for people with disabilities. When they speak of success, the tribal leaders do not speak solely in terms of a personal success; rather, they speak of success in terms of a collective effort by other community members who have expressed their own passion in the work.

APPENDIX F

Community Stories of Innovation

Innovations in Breaking Down Barriers: Parents, Self-Advocates, and Other Advocates in Action

A parent acts. Ms. Rhonda Talaswaima's story about what led to the creation of the Hopi Office of Special Needs captures the spirit of innovation from a grassroots perspective. Her pathway into the world of disabilities began with the birth of her son in 1991. Before that she did not think much about disabilities. After he was born with disabilities, her eyes were opened to the needs of children with disabilities and their families. In 1996, an event featuring a guest speaker on disabilities brought several families together who had children with disabilities. For the first time, at that meeting, she saw other family members from the tribe who had children with disabilities. Ten to twelve families connected there and began to learn and understand together how the community could better serve their children—a new generation. They started meeting in each other's houses together with other interested people; the Hopi Parent-to-Parent Support Group was thus formed. This group wanted to protect the rights of children. Culturally (historically), Hopi families kept family members with disabilities at home. Then, contact with people outside of the reservation suggested sending them away. Ms. Talaswaima noticed that this generation wants to learn and find out more. They advocated for an Office of Special Needs for two years until the office was formed. Prior to that, there was no program to protect the rights of people with disabilities.

Today, the Office of Special Needs receives federal funding for their early intervention program, which provides services for children from birth to age five. One goal of the program is to strengthen the early intervention program. They have created a culturally appropriate video, brochure, and calendar. They are working from a different angle. While most tribes operate from an elderly perspective, the Hopi program works from birth up. They recently applied for a vocational rehabilitation grant and just received notice that they received it. Now students graduating from high school can transition to a new program to prepare for employment.

The Hopi Office of Special Needs sees the great need for training in the community. One way they have increased awareness is through their Special Needs Activity Day. The Hopi Parent-to-Parent Support Group first organized this community event in 1996 as a grassroots effort. Last year 600 attended. Many residential centers bring their consumers, and local musicians play music. A Hopi motivational speaker, David Talas, who is blind, spoke at this year's event. Some event activities include a bean bag toss with visual disability simulation, a Polaroid family picture with frames made by participants in the Hopi childcare program, a wheelchair obstacle course, a fish pond, a simple lunch, T-shirts with their logo, and door prizes donated by various programs and businesses. The theme of the event is "Celebrate Diversity—Everyone is Unique."

The Hopi Office of Special Needs was recently awarded a vocational rehabilitation grant that will serve individuals with disabilities ages 16 to 64. In addition to their newly granted vocational rehabilitation program there is collaboration with the Division for Developmental Disabilities to provide support for families, such as respite and other services. There is a movement to train and certify caregivers through various service providers. This assists in moving toward self-determination, as a person with a disability can choose a family member to provide respite care. This family member can be certified to provide services, which improves choices of caregivers. A new provider, ARISE, is interested in setting up a program on the reservation. Currently, ALPINE has a day program to transport people to their arts and crafts program. This program has a unique component: tribal members with disabilities create art products and market them on the Internet. They hold open houses during the year and they've done a great job in marketing products. As with all of the other programs, this is only one component of many.

Larry Alflen of the Pueblo of the Zuni offers a different twist on innovation. The Zuni program provides a unique service, one that many tribes may wish to duplicate. The Pueblo of the Zuni territory is extremely remote and isolated. Transportation issues play a big role in the need for improved access for tribal members with disabilities.

The Pueblo of the Zuni has a program that offers a comprehensive array of services. These include supported living and assisted living services. Supported living provides one-on-one services on a 24-hour basis. Assisted living provides services for individuals with the ability to live more independently; periodic support, respite, and personal care are provided. Services are

provided in the home (e.g., assistance preparing for daily activities and respite for a family member who is the caregiver).

The Pueblo of the Zuni operates an extensive public transportation program that supports persons with disabilities as well as other members of the public. Last year they provided approximately 33,000 trips around the community. The program is funded under Section 5311, Small Urban and Rural Transportation grant, which assists with administrative monies and capital. The Pueblo owns several 15-passenger vans, some with wheelchair lifts; they are demand responsive with a dispatcher. A State of New Mexico vocational rehabilitation transportation grant provides for the use of peer drivers. The Pueblo of the Zuni also has Section 5310, a capital program for Elderly and Disabled Transportation.

The program provides up to 200 trips per day. The number one challenge is getting people to where they need to go. Unemployment is high. Among those who are employed, most work in Gallup, representing a transportation challenge to this off-reservation community. An additional challenge is keeping the vehicles operational. How do they maintain funding? They're an established program and have a positive relationship with the grant funds manager .

Twelve years ago, Mr. Alflen saw the need and decided he wanted to implement transportation services. The efforts have been successful. He looks at different options in order to meet as many needs as possible. The Pueblo of Zuni recently got approved to provide transportation under a Medicaid program. This will enable the tribe to submit a bill for transportation under Medicaid and will also help their transportation program to sustain itself.

Unemployment among the Pueblo of Zuni can run as high as 67 percent of the workforce. Finding employment is difficult; finding employment for people with disabilities is even more difficult. In response, they have created several consumer-owned businesses: a convenience grocery store and a regional recycling program. They also have a foundation grant to start a computer center. In addition, the Pueblo uses the transportation program as a mechanism to employ people with disabilities: several drivers and the dispatcher have received training through the Pueblo of Zuni's vocational rehabilitation program.

Again, the Hopi Nation and the Pueblo of Zuni are only two tribes among many who are creatively approaching the barriers they face locally in addressing the needs of tribal members with disabilities. Other tribes have conducted collaborative efforts through strategies that work, as shown in the examples below.

Effective Collaboration

Advocates and self-advocates act. Darlene Finley of the Three Affiliated Tribes emphasizes the importance of "knowing the system." To complement self-advocacy, she believes that you can be your client's best advocate if you know and take advantage of the available services, grants, and resources. Ms. Finley also suggested that consumers find one person to follow them through the entire application process from beginning to end. This helps in minimizing the confusion that can result from many people assisting one individual in the process without a single point of contact for consistency. Program staff can assist consumers more effectively if they take a case management approach and follow a client through the entire process. Ms. Finley has stated that a comprehensive knowledge of resources available has led to the success of her program.

Like the Three Affiliated Tribes, the Oneida Nation has created a very sophisticated network of program collaborations. Steven Corky West, with the Oneida Nation's Job Training Program, has advocated for a number of social service initiatives funded by the tribe such as their tribally supported One-Stop Job Center. This initiative is supported by various tribal, federal, and state funds. A combination of tribal dollars supports the center; activities and adjuncts such as mental health, alcohol, and other drug abuse services; and childcare and development programming, all of which integrate into a seamless delivery of services. In addition, Mr. West has collaborated with 125 employers on and bordering the Oneida Nation Reservation who have come together to develop a workforce diversification initiative. Employers started this initiative. The motivation may not be altruistic, but he feels that it gets the job done and it increases success for his consumers. A key for successful employment programming is the active involvement in the workforce development system. There is a close link between the Workforce Investment Act and vocational rehabilitation; together they can create a plan that is to the best advantage of the consumer. Mr. West's experience tells him that developing collaborations with the state Workforce Development Board increases the chances for success.

Supporting Self-Advocacy

Jo White of the Pine Ridge Quad Squad advocates from a grassroots level for appropriate services through state and local programs. Ms. White has developed numerous links with key service providers in the state and locally. She works closely with consumer self-advocates and listens intently to their needs. In one such case, Ms. White was confronted with consumers who use wheelchairs and were being pushed off the roads by passing cars. Motorized wheelchairs do not seem to be very practical on the reservation where there are no sidewalks. Ms. White then began to work with the housing department of her tribe to get crossing lights and sidewalks installed. These are ways that advocacy can transform a community and increase the awareness of tribal members about unmet needs. Ms. White's primary focus is in teaching and urging tribal members with disabilities to advocate for themselves. She cannot emphasize enough how important it is that consumers learn to take control of their lives by asking for the help they need.

Len Whitebear of the Cook Inlet Tribal Council in Anchorage, Alaska, feels that it is her job to advocate in support of consumer advocates by educating the community and tribal leaders about the diversity of disabilities. She believes that acceptance goes hand-in-hand with education. Much of Ms. Whitebear's time is dedicated to developing relationships with tribal leaders and community members.

Rita LaFrance with the St. Regis Mohawk Nation in New York State advocates at the state and national levels for much needed change. Chief Hilda Smoke of the St. Regis Mohawk Nation shared how advocacy at the national level assists in clarifying who addresses disability issues unique to tribal communities. As tribes seek assistance in providing much-needed services, they discover the huge gaps in accountability. The St. Regis Mohawk Nation approached the National Congress of American Indians and the United South and Eastern Tribes to ask for a resolution in support of tribes who have endorsed the American with Disabilities Act (ADA) through their own tribal laws and in challenging the Indian Health Service and the Bureau of Indian Affairs to better address disability issues.

Support from Tribal Leadership

The Oglala Nation passed ADA as a tribal resolution in 1991. It happens that one of the founding members of the Quad Squad was a tribal council member. The Confederated Salish and Kootenai Tribes passed their own version of ADA through tribal resolution in 1995. The Three Affiliated Tribes also have their own laws protecting tribal members with disabilities.

The Navajo Nation adopted such alternative tribal support. The strategy was shared in interviews with two tribal members, Mrs. Ela Yazzie King with the Gallup-McKinley School District, also a consumer and a former member of the National Council on Disability, and Mrs. Paula Seanez with the Navajo Nation's Office of Special Education and Rehabilitation. They both spoke of the landmark decision by the Navajo Nation to support its tribal members who had been underserved for so long. In 1986, under the leadership of the Navajo Nation president, a renegotiation of several land lease contracts led to a significant set-aside of monies in a specific trust fund to provide for services in eight or nine categories such as veterans' services, elder services, and services for tribal members with disabilities.

Of the eight or nine trust fund categories, only the fund account that serves Navajo tribal members with disabilities remains. Each year, the committee managing the trust awards grants funds from the accrued interest of the trust fund to agencies and programs serving the Navajo Nation. Grants are awarded for as long as three years. One of the most significant impacts of this trust was in providing seed money to develop ASSIST! to Independence and the independent living services on the Navajo Reservation. This trust has also supported transportation services, recreation services, development and improvement of rehabilitation services, and caseload reduction. While it is true that consumers on the Navajo Nation continue to experience significant barriers to service, this trust honors the responsibility that the tribal government has to tribal members with disabilities and works to improve the conditions and service.

APPENDIX G

Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or significance of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.

- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, Congress, the secretary of education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.

- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.

- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. § 12101 et seq.).

- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.

- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.

- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.

- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report.*

International

In 1995, NCD was designated by the Department of State to be the U.S. Government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became the Americans with Disabilities Act (ADA). NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that those persons with disabilities who are members of diverse cultures fully participate in society.

Statutory History

NCD was initially established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

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